# Appendices

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# APPENDIX A1: Housing Committee Report

The committee looked at housing issues along a continuum which includes Accessible Housing, Independent Living, Congregate Housing, Group Homes and Specialized Housing, Assisted Living, and Nursing Homes. The following are housing definitions adopted by the committee for the purpose of continuity and clarity of discussion.

## **Continuing Care Retirement Community (CCRC)**

These communities offer a comprehensive lifetime range of care from independent living to nursing care. Most require new residents to be healthy and able to live independently, but some allow individuals to enter at the assisted living or nursing care levels.

Independent Living, Senior Apartment Communities, Congregate Housing This housing is designed for individuals who live independently. Most congregate housing facilities do not offer health care but may assist with access to a variety of services such as home care, housekeeping, or meals, which residents pay for.

## Group Homes, Specialized Housing, &HUD Sec. 202/811

This is usually small-scale housing for those who cannot live independently, but who do not require skilled nursing care. Residents may need assistance with at least one ADL. Group homes generally house younger clients with mental retardation, mental health, or accessibility issues.

## Assisted Living Facilities, also called Adult Care Residences (ACRs)

These facilities offer housing and health-related services for individuals who need some assistance with activities of daily living, but who do not require skilled nursing care. They also serve older people who need help with activities of daily living (ADLs) as a result of cognitive or physical impairment.

#### **Nursing and Rehabilitation Homes**

These facilities are designed for people who need continuous skilled nursing or supervision on a 24-hour basis or sub-acute, respite, or rehabilitative services.

#### **Accessible Housing**

The need for housing that is accessible to those with physical or sensory handicaps overlays the entire continuum of options.

#### **Themes**

During the committee's deliberations and information gathering related to housing issues, a number of over-arching themes emerged. Underlying these themes are the following demographic projections:

The County's senior population is projected to increase faster than the national average in the next two decades. We also know that disabilities increase with age potentially resulting in the need for assistance with instrumental activities of daily living (IADL's), meal preparation, housekeeping, laundry, money management, and activities of daily living (ADL's), bathing, eating/feeding, transferring, bowel/bladder, dressing, and toileting. The projections for the increase in the senior population in Fairfax County

means that the number of individuals needing housing that offers or has access to assistance with ADLs and IADLs will increase.

The over-arching themes are listed below and impact, to some degree, all housing in the continuum.

- The Task Force must consider ways to improve both access to Medicaid funding and improved staffing for nursing homes. The quality of life in nursing homes and the quality of care offered patients is not uniformly acceptable and needs to be addressed.
- Nursing homes are licensed by the Health Department while assisted living facilities are licensed by the Department of Social Services. States are grappling with how to regulate assisted living facilities in order to protect individuals and ensure residents' safety and quality of care, while allowing providers flexibility for innovation and individualized services in their facilities.
- Seniors and individuals with disabilities requiring daily assistance increasingly find that they cannot afford the cost of assisted living in Fairfax County. Some families are moving seniors or individuals with disabilities out of Fairfax County to areas that are more affordable.
- Payment sources commonly determine the selection of housing and services.
   Ideally, one's patient/consumer needs and personal preferences rather than payment options should drive the choice of housing and services for seniors and persons with disabilities.
- Many individuals entering the field of caregiving do not speak English as a primary language, often making communication between service staff and recipients difficult. The number of residents receiving care who do not speak English as a primary language is increasing, which also complicates communication between recipients and staff.
- There is a tremendous shortage of specialized housing such as permanent supportive housing for individuals with mental illness, mental retardation, certain traumatic brain injury, cognitive disabilities, or other disabilities that require 24-hour assistance.

Significant improvements are needed in developing a coordinated, prompt, and effective response by government agencies to cases of neglect and abuse of residents in long-term care facilities.

- The agencies that should be involved are: law enforcement, adult protective services, ombudsmen, Medicare investigators, prosecutors, the medical community, regulators, and other licensing groups such as CARE.
- A collaborative environment that fosters shared training, information, and best practices about local protocols and open lines of communication about any misunderstandings needs to be established.

## Gaps

Major shortfalls were noted in the areas of Availability, Affordability, Accessibility, and Acceptability for seniors and individuals with disabilities regarding their housing needs.

## **Congregate Housing**

- In June 2000 in Fairfax County, 304 congregate housing residents received in-home services in order to stay in their apartments/homes. Residents are able to contract for a wide variety of services; however, those services are not available on a 24-hour basis as in an adult care residence (ACR).
- There are 2,768 independent living community/congregate housing units in Fairfax County with current waiting lists for each of the facilities.
- Currently there are no available living facilities specifically designed for people with physical and sensory disabilities. Many congregate housing facilities do not accommodate people with wheelchairs and other special needs.

#### **Group Homes**

- For Mental Health clients, there are not enough group homes or specialized housing units for individuals with mental health or mental retardation issues. Those who apply for one of the four group homes in the County do not have a chance of being admitted during their lifetime. The wait list is in excess of 560 and turnover is typically less than 1 every 5 years. (Source: Fairfax-Falls Church Community Services Board, FY 1999). Stevenson Place, a new 36-bed facility for permanent supportive housing, already has a waiting list of 70 individuals in Fairfax County.
- In 1999, there were 505 mentally challenged individuals waiting for placement in a specialized residential setting in Fairfax County. In 30 percent of the cases, these individuals were living with one caregiver. In 19 percent of the cases, caregivers were over the age of 70 years. (Source: Fairfax-Falls Church Community Services Board).

#### Assisted Living (ACRs)

- Many individuals who would choose to reside in an assisted living facility cannot afford to do so as the average cost for such facilities in Fairfax County is \$3,325 per month. Currently, Medicaid does not cover assisted living facilities, and there is only limited state funding. In the May 8, 2000, report on Affordable Assisted Living Needs Assessment and Evaluation of Existing Efforts, by Robert Charles Lesser & Co. for the Redevelopment Housing Authority, the anticipated total annual demand potential for affordable assisted living is 1,016 units. In addition, many individuals who have been placed in nursing homes primarily because of financially driven factors could potentially receive less costly housing services in assisted living facilities if funding mechanisms were redesigned.
- Amounts provided to low-income persons under Virginia's Auxiliary Grant program are insufficient to cover the cost of their care in Northern Virginia. The Auxiliary Grant is a supplement to income for recipients of Supplemental Security Income (SSI) and certain other aged, blind, or disabled individuals residing in a licensed adult care residence (ACR) or in adult family care to ensure that recipients are able to maintain

a standard of living, which meets a basic level of need. (VA DSS, 1988 Adult Services Program Report).

Clients do not qualify for auxiliary grant funding if their income is more than \$900 per month and, at that income, they cannot afford assisted living housing. (Affordable Assisted Living Needs Assessment and Evaluation, May 2000). Of the 168 current Auxiliary Grant recipients from Fairfax County, 121 reside outside Northern Virginia. (due to the fact that most ACR's will not accept recipients due to the low rate). The current auxiliary grant rate in Northern Virginia is \$903/month. Some ACRs will allow residents who have spent all their assets and become auxiliary grant qualified to remain in the facility rather than turning them out.

- A certificate of need helps to determine the County's requirement for nursing home beds. There is no comparable way to determine the need for assisted living (ACRs). The May 2000 report on Affordable Assisted Living Needs Assessment and Evaluation of Existing Efforts by Robert Charles Lesser & Co. estimates the annual demand from Fairfax County residents to be 610 and from outside the County to be 406 with a potential demand for affordable assisted living to be 1,016.
- It is difficult to determine the numbers of individuals waiting for assisted living vacancies. Some people may be on more than one list or may have found residency somewhere else.
- Contact with many Fairfax County ACRs revealed waiting lists with an average wait
  of anywhere from one month to one year.
- The choice of assisted care housing and its associated service delivery is too often determined by financial factors rather than by the individual needs and desires of the resident. In addition, since the needs of residents are continually changing, housing options should aim for flexibility and strive to provide residents with continuity of care. Payment options around medical issues determine service delivery.
- There is a gap in the recruitment, training, and retention of a labor force to support residents in all levels of the continuum. Resident assistants, certified nursing assistants, registered nurses, through master's level clinicians, all need initial and ongoing training. Work incentives should be offered to encourage the recruitment and retention of the workforce. The following chart shows the projections in the need for all levels of staff to support persons in residential and other health care settings in Northern Virginia.

Occupational Title	Estimated Employment Level		Openings			
	1996	2006	Percent Change	Replacements	Growth	Total
Registered Nurses	8,768	10,541	20.22%	1,210	1,773	2,980
Maids/Housekeepers	7,796	9,039	15.94%	1,400	1,243	2,640
Nursing Aides & Orderlies	5,300	6,655	25.57%	720	1,355	2,080
Licensed Practical Nurses	4,166	5,358	28.61%	880	1,192	2,070
Home Health Aides	2,649	4,059	53.23%	360	1,410	1,770
Estimate of Total providers needed in 2006: 11,54						11,540

Source: Washington DC-MD-WV PMSA (Virginia Portion) 1996-2006 – Occupation Openings

There is additional concern that the numbers of individuals choosing the nursing field as a career are declining.

County Planning and Zoning ordinances regulate the type of senior housing that can be constructed at a particular site. However, there is no specific category within the ordinance for housing for people with disabilities, limiting their availability options to nursing homes or housing for the elderly. Planning and Zoning officials are aware of this problem and are looking at possible resolutions.

#### **Nursing Homes**

- There is an affordability gap for many seniors and individuals with disabilities in paying for nursing home care. There is a limited period of time in which patients' Medicare and supplemental insurance cover nursing home costs. Beyond that period, many cannot afford the cost of nursing home care, or have to "spend down" to become Medicaid eligible. Long-Term Care insurance is one way of protecting against the increased cost of long stays in nursing home facilities.
- In Virginia, nursing home residents whose care is paid for by Medicaid (the majority of nursing home residents) and who are hospitalized have no assurance that a nursing home bed will be available to them when they are released from the hospital. It is estimated that 48 percent of the people in nursing homes need hospitalization and may be at risk for losing a bed in the interim. Unlike Virginia, sixteen states currently have bed hold policies for individuals who require hospitalization.
- The quality of care and quality of life in nursing homes can be improved. A comparison of the results of 1999 nursing home inspections shows that nursing facilities in Fairfax County had an average of two deficiencies noted by inspectors, as compared to the Virginia average of three deficiencies per nursing facility. The national average for that period was five deficiencies.

Of 12 nursing homes inspected in Fairfax County from 1999 through March of 2000, four had no deficiencies, two had one deficiency, two had three deficiencies, one had four deficiencies, one had six, and one had seven deficiencies. On a scale of 1-4,

with one meaning potential for minimal harm to four meaning actual harm, most deficiencies were graded at level two, minimal harm or potential for actual harm.

Virginia's low Medicaid reimbursement rate and the labor market situation for hiring staff contribute to quality of care and quality of life issues. In 1998, Virginia's daily Medicaid reimbursement for nursing home facilities was only \$78 per diem, which has since increased up to \$113 per diem in some facilities. According to an Urban Institute report, this *per diem* rate ranks Virginia as one of the lowest in the United States. This low Medicaid reimbursement rate severely limits resources for these facilities. Lack of resources also compromises the hiring and retention of qualified staff. Fewer or less qualified staff may be stretched in their ability to accomplish their duties, affecting the quality of care for nursing home residents.

- There is a shortage of resources for the Ombudsman Program in the Northern Virginia region in relation to other states and recommended standards.
- The Institute of Medicine recommends an Ombudsman to patient ratio of one staff to 2,000 nursing and assisted care residents.
- In Maryland, the ratio is one to 1,000.
- In Northern Virginia, the ratio is one to 3,000.
- The workload of the Ombudsman Program is increasing as evidenced by the following complaint data:

Type of Case	1997-1997	1997-1998	1998-1999
Information/Counseling	3,610	4,000	5,507
Complaint/Counseling	2,411	3,063	3,940
Complaints	86	82	94

# Appendix A2: Community Based Services Committee Report

#### **Themes**

The demand for long-term care community based services is increasing as those from the Baby Boom population explosion age. Also, there is a growing number of frail elderly in Fairfax County, as evidenced by projections for those 85 and older.

As a result of demographic, consumer, and public policy imperatives, the landscape of care for those with long-term care service needs has shifted from formal institutional settings to a wide range of community-based settings including and in addition to the home. This change, coupled with changing demographics of the County, requires a rich and diverse system of community-based services for persons with long-term care needs. Both national and state data indicate that the rate of older Americans entering nursing homes is lower than that of the past. Nursing home occupancy rates have fallen nationally from 92 percent in 1985 to 87 percent in 1995 as communities have shifted to other forms of care for the elderly and disabled. Community supports are challenged as these populations transition from reliance on institutional settings.

The intensity of client need is increasing. For example, the County's Senior Centers have seen an increase in frail elderly persons, persons with disabilities, and those with early Alzheimer's. In addition, Senior Centers have seen an increase in clients with chronic mental illness following the discontinuation of Medicare funding for day treatment. Another factor contributing to this trend is the increase in survival rates for those who have suffered a stroke and victims of severe brain injury. The decrease in the population of state psychiatric hospitals as more and more individuals return to the community is another contributing factor. These individuals need ongoing intensive treatment and medication to live successfully in more independent community settings.

The increasing diversity of the County's population has affected services offered to the elderly and persons with disabilities in the community. The percentage of households speaking a language other than English at home has grown rapidly, exceeding 30 percent in 1998. There are currently significant numbers of elderly Vietnamese, Korean, and Chinese persons in the County. As existing cultural groups begin to become assimilated, new groups enter the County and present new challenges to the human service system.

The increasing number of working women and dual income families in the County limits the availability of individuals to care for elderly and disabled persons, which creates greater demand on the community service delivery system.

Community-based services are inconsistent in their approach to setting co-payment and sliding fee schedules.

The supply of community-based services for younger persons with disabilities does not meet the demand for those services.

Greater exploration of the use of technology is needed to provide supportive long-term care services in the community.

Case management is an important conduit to community-based long-term care services. There are, however, philosophical differences in the definition of case management.

#### ADULT DAY CENTERS

Adult day centers have developed as an important service delivery approach to providing community-based long-term care services. These centers may provide a range of activities including assessment, social, recreational, and health-related services for adults with chronic and serious disabilities. They also represent an important source of respite care to give caregivers a break and/or enable them to pursue employment. Nationwide, there have been a number of demonstration projects that have illustrated that these centers can deal effectively with a wide spectrum of clients with Alzheimer's and related dementias. There is also evidence that adult day centers are cost-effective in delaying institutionalization, and participants show improvement in some measures of functioning and mood. (Source - 1999 Surgeon General's Report on Mental Health)

Nationally, over the past 30 years adult day health centers have grown in number from fewer than 100 to more than 4,000. The Robert Woods Johnson Foundation estimates that by 2010 over 10,000 adult day health centers will be required to meet the need in the community. They are typically operated under the sponsorship of community organizations or residential facilities.

In Fairfax County, the Health Department currently operates four centers located in Annandale, Lewinsville, Lincolnia, and Mount Vernon. A fifth center (Herndon Harbor House) is planned to open in January 2001 in Herndon. These centers are characterized by their strong health orientation based on a skilled nursing staffing model. The centers operate on a 7:00 AM to 5:30 PM basis 245 days per year and serve over 110 clients per day (312 unduplicated clients per year). The Health Department's Centers provide a comprehensive day program designed to assist individuals to remain in the community, to obtain maximum levels of health, to prevent or delay further disabilities, and to provide respite to family members and caregivers.

The County, participant fees, Medicaid, and the Child and Adult Food Program fund the Adult Day Centers. About 8 percent of the current service population meet the functional and financial criteria for the Medicaid waiver. Participant fees are determined by a sliding scale that is based on the State Health Department's eligibility scale. In FY99, 54 percent of the total cost to the County was recovered leaving a net cost of \$590,830. The average cost to Fairfax County was \$2,059 per older person served for the year.

One Family Respite Center in Falls Church serves Northern Virginia. This is a small not-for-profit program that serves, in part, clients in the later stages of Alzheimer's Disease.

## **Gaps: Adult Day Centers**

Availability - There is currently a waiting list of 96 persons for Adult Day Health Services. Based on demographic shifts there is likely to be an increased demand that will be somewhat addressed by the opening of the new center in Herndon. Given the current waiting list, there is only limited outreach conducted for these services. As a result, there is also an awareness of service gap which likely results in understated demand for services. In addition, providers and families report that discharge planners often do not know about adult day health care services so the option is not presented as part of discharge planning. Again, the result is a probable understatement of current demand. Finally, the 1995 Needs Assessment indicated

that some 2,400 households surveyed who had members that needed help with Activities of Daily Living (ADLs) needed but did not use adult day care.

- Availability The County is lacking in age appropriate programs for younger persons with disabilities (e.g., young stroke survivors, and younger persons who are ventilator dependent).
- Availability Adult Day Centers operate on a Monday to Friday schedule.
   Community demands necessitate service that is more wrap-around in nature.
- Accessibility There is currently no center in the western part of the County, and other parts of the County are also significantly less accessible to current centers. Caregivers report excessive transportation time to existing centers and staff reports that they are often staying 1- 1.5 hours late, waiting for clients to be picked up from the Centers.
- Accessibility There is also a cultural accessibility issue. Figures available for the month of June 2000 indicate that about 70 percent of Center clients are Caucasian, 16 percent African American, 5 percent Hispanic, 4 percent Asian, and a remaining 5 percent make up of other ethnic groups. June figures also show that 85 percent of clients speak English; however, 15 percent speak no English. Some languages spoken by clients are not covered by the staff at the centers. Communication is attempted through gestures, but this is not always successful.
- Acceptability The cultural accessibility gap also most likely presents an
  acceptability gap. Persons from diverse cultures may choose not to use the
  services due to the communications barrier as well as the absence of others
  from their own culture.
- Affordability There appears to be a lack of knowledge that long-term care insurance covers adult day health services. A review of 10 long-term care insurance plans indicated that all plans covered adult day health care.

The Veteran's Administration currently contracts with only one County-operated center and one private center (Leewood). Adult day services and transportation for clients at these two centers are fully covered by the Veteran's Administration.

#### **SENIOR CENTERS**

Senior centers provide an environment where persons over the age of 55 can maintain social, physical, and emotional well-being through recreation, socialization, and life skills enhancement programs. Historically, senior center programs have not been designed to serve the very frail or persons requiring extensive monitoring or support services. More and more, however, senior centers, as a result of demand and lack of alternatives, are being asked to serve a more frail population and those requiring more extensive monitoring.

There are currently 13 Fairfax County Senior Centers operated by the Department of Community and Recreation Services (CRS). These centers serve a registered enrollment of approximately 7,000 seniors and provided approximately 208,000 visits in 1999. Centers provide noontime meals, transportation, opportunities to socialize, and a

variety of activities for senior citizens. Admission to Centers is free; however, there is a charge for some Leisure Enterprise activities. The Centers do not maintain a waiting list. All who want to come are welcome.

In Fairfax, there is also an extensive network of senior "clubs" that provide an array of socialization and recreation opportunities to seniors throughout the County. In addition, there are several community-operated senior centers. Notable among these programs are those targeted specifically at seniors from a particular culture and language. This enables seniors who do not speak any or limited English to socialize with seniors from their own culture. There is a growing desire among many culturally based community groups to sponsor senior center activities. Some small community-operated centers (e.g., the Korean Central Presbyterian Church's Senior Center) are not eligible for food reimbursement under the Older Americans Act.

### **Gaps: Senior Centers**

- Availability There is an availability gap for senior center services targeted at residents who speak little or no English. The Korean Central Presbyterian Church's Senior Center Program serves over 200 seniors two days a week entirely with volunteers. This is well above the program's intended capacity. Growth and expansion of these programs to other cultures and to five day per week efforts is often constrained by the lack of FASTRAN services to support these programs.
- Availability Volunteer service supplements limited staff resources at the County's Senior Centers. There is a staff resource gap for emergency situations. Patient demands necessitate at least two staff persons, but centers sometimes have only one person on duty. In addition, about 80 emergency calls to 911 have been made in the last year. When the sole staff person is dealing with the emergency situation, he/she is unavailable to oversee and assure the safety of other Center clients.
- Accessibility Due to the frequency with which persons over 65 and persons with disabilities do not drive, FASTRAN provides door-to-door service to Senior Centers. In fiscal year 1999, FASTRAN provided approximately 105,000 rides to Senior Centers. However, scheduled coverage is not comprehensive. (e.g., Transportation to Hollin Hall is provided only one day per week). FASTRAN will not currently cross catchment areas for centers. This creates a secondary acceptability gap as different centers have different types of populations (more or less frail). Since transportation is not offered across catchment areas, seniors have limited opportunity to attend centers where peers of a similar functional level attend. As a result, staff reports that some forgo attending at all. Recommendations from the recently initiated Senior Transportation Initiative may address the transportation gap for this service.
- Accessibility Clients at Senior Centers are a reflection of the County's diversity. Higher percentages of households speaking a language other than English at home are found in areas inside or closer to the Beltway. For example, participants at the County's Springfield Senior Center speak fifteen different languages. This presents a challenge for planning and service delivery. With only two staff people at each senior center, the ability to cover other languages is severely constrained. Despite the diversity of the populations served at the centers, there are cultural and language barriers that exist which constrain access for some residents. There are also

acceptability issues as members of a culture, particularly seniors, prefer to congregate with persons from a similar background.

• Acceptability - Senior Centers are consistently being pressed to take an increasing number of higher need persons. This is the result of many factors including the end of Medicare funding for day treatment several years ago, waiting lists for more appropriate services, and affordability issues for home-based care services. Families are looking to these centers for more intensive services as an alternative to other forms of long-term care. This creates a variety of best practice quality issues and presents significant challenges to the small staff of these busy centers. As an example, early Alzheimer's clients occasionally wander off site into the community requiring the full attention of at least one of the two staff people. This creates safety issues not only for those who wander, but also for the other clients at the center.

Others considered to be higher need than the centers were designed to accommodate include the chronically mentally ill and the frail elderly. A recent survey conducted by Community and Recreation Services staff indicates that there are an estimated 119 persons attending senior centers who have needs that the centers were not designed to meet. Two centers have as many as 17-25 high-need attendees per day. This same survey indicates that the primary sources of these referrals are the major public human service organizations (Family Services, Alcohol and Drug Services, Mental Health and the Disability Services Board). This reflects the gap in alternative service choices for these clients.

There is no established standard or set of assessment criteria to determine the most appropriate service for an individual along the long-term care continuum.

#### THERAPEUTIC RECREATION SERVICES

Therapeutic Recreation is the use of activities to promote health, prevent impairment and dependence, maintain optimal functional capability, and remediate leisure-related problems with disabilities and other limiting conditions. While some non-County service programs have adopted a formal therapeutic recreation approach, the principle provider of these services is the County's Department of Community and Recreation Services. CRS provides over 35 programs to some 1,500 individuals aged 3 and over in Fairfax County. The Department has five Certified Therapeutic Recreation Specialists and over 100 non-merit employees providing services. The County involves the community in Therapeutic Recreation by recruiting volunteers, obtaining grants, and obtaining sponsorship of programs.

## Gaps: Therapeutic Recreation

 Availability - Therapeutic Recreation Services sponsored by the County can no longer expand without additional full-time staff. Increasing demand has resulted in waiting lists for programs, including those listed below (as of March 2000):

PROGRAM AREA	NUMBER	COMMENTS
	ON WAITING LIST	
Weekly Social Clubs	32	Individuals FY 2000
Summer Recreation	20	Families FY 2000
Saturday Recreation	16	Families FY 2000

- Availability Therapeutic Recreation Specialists currently have an active caseload of 300 Child Specific Teams. This caseload has increased 200 percent in the past year.
- Availability The closest school with a Therapeutic Recreation program to educate future specialists is located in Richmond.

#### **HEALTH SERVICES**

Health services are among the most important of the community-based services supporting long-term care needs. Fairfax, as a whole, is blessed with a well-developed primary and specialty health care environment. The 1995 Community Needs Assessment estimated that 10.7 percent of County residents were uninsured. Over one-quarter of all households earning less than \$25,200 have at least one person without health insurance. Data also indicates that seniors in Fairfax were more likely to receive needed health care than the population as a whole, reflecting the higher incidence of health insurance coverage (primarily Medicare) present for the elderly as a group.

There are various gaps in the health care network that relate to long-term care.

Gaps: Primary Health Care

Availability -The Health Department's Community Health Care Program (CHCN) is a key service designed to provide affordable primary health care to uninsured and underinsured Fairfax residents. The Fairfax County Community Health Care Network is a partnership of health professionals, physicians, hospitals, and local government. This Network offers primary health services to low-income, uninsured County residents who cannot afford primary medical care services. The Health Department operates three health centers located in South County, Bailey's Crossroads, and North County through a contract with a private health care organization. The target population is the "working poor." Currently, 20,395 residents are enrolled in the Network.

One year ago (1999), 5.2 percent of the 20,000 participants in CHCN were over 65 years old. This figure has now grown to 6.6 percent. The elderly (65+) population is the fastest growing sector of Fairfax County's population, and is expected to increase to approximately 13 percent by 2010. Approximately three percent of those served are enrolled in Medicare.

Currently there are over 900 persons waiting for enrollment at the Bailey's CHCN center. There are no waiting lists at the other centers.

- Availability The County's CHCN has 290 participating specialists. However, the Network currently lacks adequate numbers of specialized medical practitioners in the areas of Ear, Nose & Throat (ENT), cardiology, and endocrinology.
- Availability Very few medical practitioners are identified as specializing in the field of geriatrics. According to the Washington's Physicians Directory, the Northern Virginia area has only 33 geriatricians.

Accessibility - Communication with clients who do not speak, read, or write comfortably in English is a challenge for providers of health services. Even when language barriers are addressed, differences in cultural norms and beliefs can present challenges as well. At the Bailey's center, only 25 percent of the clients consider English to be their primary language. Primary languages spoken by clients, among others, include Spanish, Farsi, Vietnamese, Arabic, and Korean. Personal medical services are best delivered in a person's primary language that is his/her "language of intimacy." The struggle to meet cultural demands creates a tension between the standard "template" time for doctor visits for English-speaking clients and the actual time required for interpreted visits.

# Gaps: Availability and Affordability of Medications, Medical Supplies & Equipment

- Affordability Medicare does not currently cover prescription drugs, and private insurance co-pays are often prohibitive. There is also an affordability gap in terms of economic barriers faced by customers to purchase over-the-counter medications.
- Many elderly and disabled residents in the County have diets that include liquid meal supplements (e.g., Ensure). Affordability may be an issue for those using these supplements due to the high cost per can.
- Availability of durable medical equipment is an issue. To address this issue, the Community Health Care Network has developed a Patient Assistance Fund. Currently, this fund has only \$6,000.

### **Gaps: Dental Services**

- Availability The need for dental services is critical, as the demand for dental services exceeds the available supply. The County Health Department operates dental units serving children only.
- The Northern Virginia Dental Clinic provides general dentistry services including examinations, emergency care, x-rays, fillings, extractions, root canals, and minor gum surgery on a sliding fee scale to low-income adult residents of Northern Virginia. The clinic is a regional partnership between the Northern Virginia Dental Society, local public and non-profit human service agencies, and area local governments. It is staffed by volunteer dentists and hygienists.

The Northern Virginia Dental Clinic primary funds come from the Arlington Health Foundation. The Clinic receives grants through United Way and the Virginia Health Care Foundation as well as contributions by local dentists (averaging \$25,000 per year). The Clinic is also supported by funding from the local governments in Fairfax County, Fairfax City, Falls Church City, Alexandria, and Arlington. This dental clinic operates under a formal agreement with area cities and counties. These governments have designated social service agencies to screen potential patients for eligibility and to then refer them to the Clinic. There is a six-month waiting list for the services provided by this clinic.

The Northern Virginia Dental Society provides a dental care referral service for seniors (60+). Referrals are made for seniors with Medicaid cards to volunteer dentists who will provide dentures at a reduced rate.

- The County's Office of Partnership (OOP) contracts with Northern Virginia Family Service (NVFS). Two Social Workers receive about 3,000 requests for care a year. Most requests are for dental care, although some requests are for medical care. Clients are either enrolled in the Bailey's dental clinic, which has a waiting list, or they are referred to private dentists for discounted care. Clients must be low-income County residents. The total amount supplied by OOP is \$3,595. NVFS attempts to supplement this funding through work with ecumenical groups.
- Younger children with profound disabilities lack dental care.
- Virginia is one of seven states that limit care provided by dental hygienists. This has the effect of constraining dental care that could otherwise be available.
- Affordability Due to high cost of dental laboratory services, even care provided by the Northern Virginia Dental Clinic can be costly.

## **Gaps: Vision Care**

- Availability There is a vision clinic at Fairfax Hospital that is conducted in cooperation with the Lion's Club. The clinic serves all ages; however, most clients are low-income elderly persons. The clinic offers surgery (including cataract surgery) and treatment for glaucoma. Clients are screened by the Health Department and must meet financial eligibility criteria. Most clients are foreign born. There is currently a three-month waiting list for service.
- Affordability While adequate supplies of eyeglasses are available for very low-income residents, there is a lack of supply for others who may find the cost prohibitive. If a person has a prescription for eyeglasses and is unable to pay, he/she can be referred to the Lion's Club. There is, however, a \$20 charge for glasses and a 3-4 month waiting list.

## **Gaps: Speech and Language Services**

- Speech and Language Pathology Services of the County's Health Department currently operate at three locations Mount Vernon, Fairfax City, and Reston. Services include screenings, diagnostics, consultations, and referrals. Additionally, the Health Department sponsors (at no cost) Stroke Club Support Groups to persons who have had a stroke and to their families. Ninety percent of these stroke victims are over 55 and most are English speaking.
- Availability Acute patients are seen immediately. There is a significant waiting list for ongoing speech therapy.
- Awareness Although the service is used to capacity, there appears to be a general lack of awareness of the speech and language services provided by the County.

Accessibility - There is a language-based accessibility gap for non-English speakers.
 Language issues can hamper speech therapy for stroke victims. Non-English
 speaking elderly are not likely to learn English, and speech therapy through a
 translator can be very difficult. Too often, these victims suffer social isolation.

Gaps: Audiology Services

- Availability the Health Department offers Audiology Services for adults with communication difficulties at three locations – Mount Vernon, Fairfax City, and Reston. Services that are offered on a sliding fee schedule include screenings, diagnostics, hearing aid evaluations, consultations, and referrals. More than 50 percent of the patients over age 55 have hearing issues. Currently only two audiologists serve the entire County, which challenges the department's ability to meet demand.
- Availability The cycle time for responding to hearing aid requests is an issue.

#### **COMMUNITY MENTAL HEALTH**

According to the National Center for Health Statistics, the average life span in the United States has increased from 47 years in 1900 to more than 75 years today. These trends will continue as the number of older Americans increases with the aging of the baby boom generation. The majority of older people cope constructively with the physical and cognitive changes associated with aging.

Further, according to the Surgeon General's 1999 report on mental health:

Research has contributed immensely to our understanding of developmental processes that continue to unfold as we age. Drawing on new scientific information and acting on clinical common sense, mental health and general health care providers are increasingly able to suggest mental health strategies and skills that older adults can hone to make this stage of the life span satisfying and rewarding.

The report goes on to stress, however, that despite this general capacity for sound mental health among the elderly, just under 20 percent of persons aged 55 and older experience a specific mental disorder that is not part of normal aging. Data indicates the following prevalence rates in persons over age 55:

Anxiety Disorders 11.4 percent Major Depressive Episode: 3.8 percent

Unipolar Depression 3.7 percent Bipolar I and II .3 percent Schizophrenia .6 percent

Somatization .3 percent

Severe Cognitive Impairment 6.6 percent

Prevalence - Any Disorder 19.8 percent

Applying these prevalence rates, approximately 35,000 Fairfax residents over the age of 55 are currently experiencing a specific mental disorder. By 2010, assuming that prevalence rates hold steady, that number will grow by almost 62 percent to over 56,500

people. This will significantly challenge the community's capacity to respond both in primary health care settings (the first line defense for detection of many disorders) and within the mental health system itself.

Currently, the Community Services Board (CSB) targets a small proportion of its resources towards specialized services for older adults. Of the 451 staff positions in mental health, 10 (nine therapists and the equivalent of a full-time Psychiatrist) positions are targeted to serve older adults. Ongoing Psychotherapy and clinical case management in the home, with occasional home visits with psychiatrists, is available from all the Mental Health Centers. The Mt. Vernon Mental Health Center sees about twice the number of homebound clients as either Woodburn or Reston.

Currently, the caseload of older adults who receive psychotherapy and clinical case management totals 290, with 105 of these being served in the home. In addition to this ongoing work, CSB-Mental Health has developed a Rapid Response Service that provides 1-3 home visits at the request of other agencies. This enables the requesting agency to get impressions of the mental health status of elderly persons and caregivers at risk. It also allows the therapist to build an alliance with fearful clients who are not ready to have a case opened due to stigma or fear of being institutionalized. A total of 35-40 cases per year are served in this manner.

About 310 older adults are served in the CSB's various Adult Residential Service programs. Another 10-15 clients are receiving Community Support Services. Overall, targeted services for older adults represents a relatively small share of the CSB Mental Health caseload. There is a limited cross-cultural staffing capability within the CSB for this older population. The 7 Corners Satellite office of Woodburn has a half-time Spanish speaking therapist and a half-time Vietnamese speaking therapist.

The non-profit Center for Multicultural Human Services enhances the community's crosscultural mental health capacity. It provides both culturally appropriate psychological and psychiatric services. However, its program literature indicates more of a family and child orientation and does not mention a geriatric specialization.

## **Gaps: Community Mental Health**

- Availability The Community Service Board's capacity for mental health services targeted to the elderly is limited and used to its full capacity. CSB staff reports that existing clients could utilize additional services if overall capacity were expanded. There is a 4-8 week waiting list for counseling, therapy, and medication appointments with a doctor. As the elderly population grows, so too will demand for services.
- Availability Currently, the County has no Geriatric Day Treatment Program.
- Awareness There is limited outreach and education regarding depression and other mental illnesses that affect the elderly and others with long-term care needs.

#### **CASE MANAGEMENT**

Case management services are a set of activities that include outreach, service entry, assessment, service planning, arranging/linking, and monitoring that are designed to help an individual receive appropriate services in an effective and efficient manner.

When these activities are offered within the context of a single service discipline and are focused on a specific service goal, the activities are often referred to as "care management." When the activities involve the coordination of more than one set of services and involve multiple service goals, the activities are almost always referred to as "case management" services.

These umbrella activities can be delivered in the public, private, and nonprofit sectors. Individuals and families often (willingly or out of necessity) perform these roles for themselves or for their loved ones. Different service providers have different approaches, targeted populations, and practical definitions of what case management services mean. This variation in perspective around a common set of activities is often confusing and is the cause of much misunderstanding within the human service system. Simply stated, having access to case management does not mean that you necessarily have access to needed services.

Some providers of case management serve primarily as information brokers and coordinators of services between providers. This can be particularly helpful in a long-term care service setting where an individual or family may suddenly be confronted with both unfamiliar problems and the need for a range of unfamiliar services. In the long-term care service delivery system, there are public non-profit community-based and private for-profit providers of a "brokerage model" of case management services. Other providers of case management function as authorizers of service. They are actually empowered to arrange, enroll, and start services. They can provide a "one-stop-shopping" feel to meeting a set of services needs. The County's Care Network for Seniors is an example of the "service authorization" model of case management services.

Most of the major human service agencies involved in long-term care service delivery provide some form of case management services for their clients. This is true for the Health Department, the Department of Family Services, and the Community Services Board agencies. Non-profit organizations such as the Center for Multicultural Human Services and the Korean Community Service Center provide some form of case management services that address the needs of various multicultural communities. Organizations such as Brain Injury Services provide case management activities designed to obtain and coordinate services that support the attainment of self-sufficiency for individuals with a specific disability.

There is currently no waiting list for long-term care case management services in the Department of Family Services or for Medicaid funded targeted case management services in CSB-Mental Health Services. There is, however, a significant waiting list for CSB-Mental Retardation case management services. Brain Injury Services has 50 on the waiting list for case management services.

#### **Gaps: Case Management**

- Awareness There is a general lack of awareness on the part of the public about the availability and benefits of case management services. This knowledge gap can significantly affect appropriate and timely access to services.
- Availability and Acceptability While in some service contexts there is no waiting list for case management services, in others the wait may be extensive. Often what you get, and for how long, is dependent on income, insurance, or diagnosis. Case

management services can be critical services for supporting long-term care clients and their families through difficult and challenging times.

Availability and Acceptability - Within the public sector (and to a certain extent, the private sector as well) there is variation in definition and approach to long-term care case management services. There are varying levels of commitment to multidisciplinary approaches to case management. In different parts of the County, case managers have varying access to professionals from other disciplines. This variation and absence of consensus regarding the best practice model results in an uneven delivery of services.

#### DISCHARGE PLANNING

Effective hospital discharge planning, particularly from a hospital stay resulting from major illness, injury, or surgery, is an essential element in transitioning the client back to home and community. In the absence of appropriate planning, a patient's recovery may be hampered, their health and well being jeopardized, and caregivers may be unduly stressed.

## **Gaps: Discharge Planning**

- Availability There is a lack of an appropriate community facility to support young persons with disabilities following a hospital discharge. Currently all communitybased transitional options are geared to seniors.
- Acceptability Discharge planning is often insurance-driven. This includes Medicare and Medicaid as well as private insurance. Patients are often discharged before they are fully ready or their families/caregivers are ready and equipped to receive them.
- Awareness There is an awareness gap in terms of knowledge of community services on the part of hospital-based discharge planners. This is evidenced by the fact, among other things, that there are almost no referrals for Adult Day Health Care from the hospital discharge process.
- Acceptability Hospitals are more likely to discharge patients to nursing homes but rarely screen for other long-term care options. The focus appears to be on shortterm post hospital care planning. This system problem can result in unnecessary interim placements and delay in transitioning the client into a more permanent environment.

#### **EMERGENCY PLACEMENT SERVICES**

There is a continuum of services in place for elderly, incapacitated, and persons with disabilities who are experiencing a crisis and need supervised care:

- The new contract for in-home services provides for an emergency response of two hours for an aide to arrive at a client's home.
- Adult Protective Services (APS) has access to a separate room at Mondloch House.
   The room has a cot for a caregiver and an attached handicapped accessible bathroom with a roll-in shower.

- The County (DFS) maintains a contract with Sunrise Assisted Living for persons who are in need of the assisted living level of care. The contract limits placements to one week.
- The County (DFS) maintains a contract with Fairfax Nursing Center for persons in need of nursing level care. Placement is limited to 14 days.
- The Community Homes for Adults program (adult foster care) has a provision for emergency placements.

## **Gaps: Emergency Placement Services**

 Availability – There is a need for an appropriate community placement (regional) for seniors following a mental health discharge.

#### **CENTERS FOR INDEPENDENT LIVING**

Like the nearly 400 Centers for Independent Living across the country, the Endependence Center of Northern Virginia (ECNV) is a community-based resource and advocacy center managed by and for people with disabilities. ECNV offers an array of independent living services including peer counseling, facilitated support groups, advocacy, information and referral, and personal assistance services.

#### **Gaps: Centers for Independent Living**

 Accessibility -The Endependence Center of Northern Virginia has one location in Arlington. Fifty-two percent of the clients of this center are Fairfax County residents. Transportation is a barrier for some County's residents to accessing the services of this center.

#### FAMILY ADULT DAY CARE

Family adult day care is an emerging community-based service. It is similar in nature to family child day care. Care services are provided in a small group setting in a private home. There is little information or data about this service. It is not currently widely available.

This service warrants additional monitoring and study and provides a potential new alternative to meet community-based long-term needs.

#### **Gaps: Family Adult Day Care**

- Availability This service is only available on a very limited basis. There is also very little consumer awareness of this as a service alternative.
- Acceptability The overall consumer acceptability of this service is untested. There
  are no current licensing requirements to become a provider and no formal monitoring
  of for-profit vendors of this service.

#### PERSONAL CARE ASSISTANCE

Personal/attendant care assistance involves help with a variety of activities, such as getting out of bed, bathing, and meal preparation. In addition, this form of attendant care support also extends out of the home to enable individuals needing long-term attendant assistance to participate and function in the community.

## **Gaps: Personal Care Assistance**

- Availability- This form of attendant care is a relatively low paying job and there is both a current and projected shortage of this kind of worker in the employment market. Family members may be either nonexistent or unavailable to fill the gap and provide emergency back up when personal care assistants are unavailable. To address the shortage of workers, the Endependence Center of Northern Virginia (ECNV) has developed a Personal Care Assistant Registry, or list of individuals available to provide personal assistance. Despite the Registry, however, availability of personal care assistance remains an issue.
- Affordability Currently, 200 persons are on the wait list statewide for personal care assistant funding. The median income of Fairfax County's older population is 69 percent of the County's median income. Frequently persons with disabilities are required to provide in-kind services (e.g., room and board) to assistants in order to afford personal care services.

# APPENDIX A3: In-Home Services Committee Report

## **Themes**

The In-Home Services Committee focused on the services that are provided in order to enable the long-term care consumers to function to the best of their ability in their own homes. Recurrent themes throughout the discussion of demands and availability of inhome services in Fairfax County include:

- There is a lack of affordable, acceptable, available in-home care providers, particularly for personal assistance and non-skilled care. Issues include lack of training and multiple skill requirements, language/cultural differences, coverage hours and days, eligibility of certain clientele, and limitations on forms of payment subsidies.
- There is lack of awareness or knowledge about the in-home services that are available in the County and how to access them.

The projections for Fairfax County indicate the population of elderly is growing, particularly the very aged (85+). Since age is the main factor affecting likelihood of having a disability and of the need for in-home assistance, demand for these services will continue to grow.

In 1998 there were 100,189 persons in Fairfax County who were either elderly, disabled, or both (not counting persons in nursing homes and assisted living, which total 4,580 beds in 2000). Of this population, 8,997 were age 0-19; 20,973 were age 20-64; 14,556 were both over 65 and disabled; 55,663 were over 65 and not disabled. This number is estimated to grow to 171,789 in 2010.

In 1998, an estimated 17,350 persons needed assistance with the Activities of Daily Living. Approximately 50 percent of this population is over 65. This number is expected to grow to 24,280 in 2010.

The growing culturally and linguistically diverse population presents a number of additional challenges for meeting in-home service needs. This is true due to the disproportion of limited-English speakers as providers, as well as the needs of non-English speaking persons needing assistance.

In addition to general shortages of affordable in-home service providers due to the tight labor market, it is even more difficult to locate and match persons needing assistance with providers who are compatible in language and culture.

The variance in coverage by private third-party payers creates an affordability gap for inhome services for many that need it. For the nation, the distribution of home health expenditures shows that Medicare is the largest payment source, followed by out of pocket, Medicaid, other private funds and, lastly, private health insurance.

Given the number of low-income elderly and disabled persons living in Fairfax County, it would appear that Medicaid is underutilized as a source of payment for home-based long-term care services. Of those who are receiving Medicaid, only about 300 persons utilize Medicaid waiver services for home-based care in Fairfax County. In January

2000, there were 4,213 Medicaid recipients in the Blind and Disabled category, and 6,521 in the Age 65+ category.

#### **Health Care – GAPS**

<u>Description</u> – This includes services available in the home including Occupational Therapy, Physical Therapy, Respiratory Therapy, Speech Therapy, Hospice, Skilled Nursing, Prescription Drugs, Medication Management, Dietician, Home Delivered Meals and Nutrition.

As with other services, a person who is low-income and disabled and qualifies for Medicaid, or is over 62 and has Medicare Part B, has many of these services covered. Persons under age 62 who are disabled, must have been receiving SSDI for two years before they are eligible for Medicare. A middle-income adult with disabilities, younger than 62, is more likely to be self-paying for these services, all of which are very costly.

Prescription Drugs – Older persons use prescription drugs three times as frequently as the general population; their per capita expenditure on medications is fourfold. Medicaid covers most prescription drugs, usually with a \$1 co-payment. For many patients there is an affordability gap as Medicare does not presently cover prescription drugs, and private insurance co-pays are often prohibitive. Medi-gap drug plans commonly have a \$250 deductible, 50 percent cost sharing, and benefit caps.

Medicare patients at Affordable Health Centers (471 patients), who have a long-term need for a costly drug may be referred to a social worker who will talk with their physician to see if a less expensive drug can be used and may try to connect them with a pharmaceutical company's indigent drug program. Coordinated Services Planners (CSP's) also work with patients to obtain funds for medicine from community-based organizations, but this is generally limited to one-time assistance. The Medicine Program offers assistance to some qualifying low-income persons by contacting drug companies to obtain free or reduced cost medications for those participating in the program.

- Skilled Nursing is covered by Medicaid and by Medicare, but the definition of qualification for skilled care may leave some availability gaps. County health nurses do an assessment of physical and health conditions and make recommendations for skilled nursing services. They provide ongoing monthly assessments for 100 patients who are receiving bath and respite services. Hospice presently serves 75 terminally ill patients without health insurance.
- Projected needs for nurses to replace retirees, coupled with a reported continuing decline in enrollments in nursing schools, indicate that shortages of skilled nurses may become even more serious in coming years.
- Home delivered meals are covered by the Older American Act (60+) through Meals on Wheels and is available on a sliding fee scale. In 1999, 684 clients were served. A small number of disabled adults are served through privately donated funds, but the demand exceeds funding availability for disabled adults.

Deliveries are by volunteers so there are sporadic gaps in availability of services. Gaps occur in availability and acceptability due to limitations on services that are available. Home delivered meals are not available to persons under age 60, on weekends, or for special diets. Provision of a hot meal at noon and a cold evening meal is not acceptable for many seniors.

Additionally, there is no selection for ethnic food or cultural considerations. Existing meal services cannot accommodate some personal situations, such as physical complications (*e.g.*, stroke victims who have difficulty swallowing) that may lead to nutritional problems.

• There are gaps with Medication Management in the home.

Medicare and Medicaid under skilled care cover teaching families or individuals how to administer medication. Medicaid waiver services cover the supervision of medication. County home-based care includes medication supervision as a service; however, it may not cover medication management. Non-skilled home care providers may supervise the medications, once prescribed and dispensed by a physician or pharmacist. Misuse, including overuse or erratic use, of medications may be a factor in up to 50 percent of hospitalizations. Also, there is a gap in acceptability of service available for diabetics for insulin management.

- Physical/Occupation/Speech Therapy are provided as a home service when covered by Medicaid, Medicare, or private insurance. Home health agencies report that there is presently not a waiting list for these services at home for patients receiving other home health services. However, if not covered by insurance, it becomes very costly. Also, the number of approved visits may not be adequate to meet patient needs.
- Liquid Nutrients Delivery of liquid nutrients is covered by the Older Americans Act (60+). In 1999, 459 clients were served and there is presently no waiting list. This service is available on a very limited basis for younger disabled adults through donated funds. As a supplemental source of nutrition, liquid nutrients may not be covered by insurance, making this option unaffordable.
- Dietician This is not covered by Medicare or Medicaid. Some managed care plans provide coverage for a dietician visit. Nutrition counseling is usually provided by the nurse during home visits. Only in very challenging cases would home health agencies request a home visit by a dietician. This may present an availability gap for some patients such as diabetics.

#### **Independent Living Supports – GAPS**

<u>Description</u> – This includes assisting transition to independent living for the newly disabled (i.e. those returning from institutions) as well as those experiencing a decline in functional ability due to chronic conditions. Transitional assistance may include monetary and in-kind support for initial establishment of a household and assessment and modification of an existing home to enable independent living.

Training for the individual to learn how to live independently with a disability is essential, but funding for this service is limited or not available in Virginia. A recent AARP survey of Americans age 45 and over indicates that 83 percent would like to stay in their home

as long as possible and nearly one in four report that a member of their household will experience problems getting around their home within the next five years.

 Accessible Housing is in short supply and this has been intensified by the tight housing market. There are long waiting lists for all low-income housing, and finding accessible housing is even more challenging.

In July 1999, the Housing Authority reported 1,106 handicapped/disabled persons on its waiting list. A partial survey by the Fairfax Area Disability Services Board staff has found that about 6 percent of the apartment units in the County are accessible as reported by apartment managers. Only 10 managers reported having an available, accessible apartment at the time of survey; nine of these rented for between \$850 and \$1,030. Eighty-one percent of the accessible one-bedroom apartments cost \$700 or more per month. Most homes - single family, townhomes, and apartments - are designed for person who can climb stairs. Awareness about how to retro-fit homes for people who have become disabled and how to finance these modifications is not widely available.

- Home Modification and Repair Assessment for safety and access is covered by Medicaid only if prescribed by a physician as medically necessary, and is not covered by other sources. Once the assessment has been done, it is up to the client to obtain the services of a contractor to do the work. Presently there is not a mechanism for certification or referral of qualified contractors who are experienced with home modifications for access and safety.
- The RPJ Housing Development Corp. Hearts & Hammers program provided low-cost (or urgent) repairs and modification to 11 homes in 1999, and to six so far this year (80 percent of the participants are at poverty level). Currently 20 homes are on the waiting list.

Major work is provided annually as a volunteer home repair service through the RPJ Housing's Christmas or Sukkot in April program, which served 69 homes in 1999 and 70 in 2000. This program addresses accessibility improvements, safety modifications, major system repair (roofs, heating, etc), repair of code violations, and some preventive maintenance. Labor hours per home are 160-300, with \$1,500 average cost of purchased materials.

The County's Home Repair for the Elderly estimates that 80 homes are repaired each year with an average per home materials cost of \$500 and up to a week of labor provided. This also serves disabled adults. There is a waiting list of 40 homes needing repairs. Community-based organizations providing assistance with home repairs also report waiting lists.

 Home Improvement Loan Program (HILP) – County funds are available for home owners to adapt their homes to make them accessible; however, these funds are not available to renters to modify their own apartment or to improve external access to the building.

HILP receives 200 applications and processes between 75-100 loans per year. Not all loans are for the elderly or disabled, and loans may cover other than safety or access modifications. The minimum loan amount is \$2,500 and loans for last year

averaged \$19,000. Lending requirements may prevent persons with inadequate income or bad credit from qualifying for these loans.

 Training for individuals with disabilities to learn how to adapt to living independently is not generally available or affordable in Fairfax County.

Supports and financial assistance to set up a household are available through community-based organizations and the County, including emergency assistance such as first month's rent, security deposits, and budget counseling. DFS has contracts with vendors for moving and storage services. However, based on delayed payments by clients and excessive burden, it is increasingly difficult to find storage. Some community-based organizations offer assistance with transitional assistance including packing, moving, and storage. There is currently a waiting list for many of these services.

#### Personal Assistance Services - GAPS

<u>Description</u> - Personal Assistance Services can include a variety of specific services provided to assist an individual with activities that he or she is not able to do independently due to a disability/disabilities. These services may include assistance with bathing, toileting, dressing, transferring, cooking, shopping, and transporting, and for some persons with cognitive impairment. There are significant gaps in availability, affordability, accessibility, and acceptability of personal care assistance services in Fairfax County.

 Medicaid and Medicare provide only limited coverage for personal assistance service resulting in availability and affordability gaps. Medicare does not cover housekeeping services and Medicaid covers in a limited way.

Eligibility for Medicaid coverage for in-home services differs for the Consumer-directed waiver and the Personal Care waiver. Both require that a person need assistance with ADL's and an IADL and be income qualified. For the Consumer Directed Medicaid personal assistance waiver, one must be competent to manage one's own care. Many persons needing assistance do not meet both of these criteria. For many who qualify for Medicaid, the co-pay makes this service unaffordable.

- There are approximately 300 recipients of the Elderly and Disabled Waiver in Fairfax County, with no waiting list. However, the mental retardation waiver has a waiting list, and the Department of Rehabilitative Services (DRS) has a waiting list for personal assistance services. In addition, DRS does not provide personal assistance services over the long term for a person who works at home.
- Labor supply and experience shortages limit the availability of personal assistance services, including certified nursing assistants.

Home health companies cannot find enough qualified individuals to meet the demand; plus, the job is low-paying and can be highly transitional. The inadequate supply gap for home health agencies compounds the lack of adequate back-up services. Agencies do not offer backup services, and long-term care insurance policies require persons to use agency staff. The resulting very large gap for backup

service can create a crisis for the disabled consumer or a care-giving family if a scheduled service cannot be delivered due to an emergency.

The Endependence Center has developed a Personal Care Assistant Registry in order to address the shortage of assistants in the market, but often those listed on the registry are quickly hired full-time and then are no longer available to serve as back up. Acceptability gaps may exist due to cultural and language barriers. Availability gaps are more severe in certain parts of the County.

- While training has been developed for some specific types of personal assistants (Cognitive Coaches, Certified Nursing Assistants), there is presently not a training or certification program for other types of personal assistants. Because the State's Personal Assistant Program is consumer driven, it is left up to each client to hire, train, and orient their own primary personal assistant and back up. There is a lack of infrastructure to develop and cultivate a supply of personal assistants, and payment restrictions prohibit sharing of personal assistants.
- Affordability, accessibility and acceptability gaps result from the high cost of personal assistants. Cost is excessive for many younger disabled persons, and in-kind services such as room and board may be offered as an incentive.

The labor supply is inconsistent for both younger and elderly persons who need personal care assistance, and there may be cultural and language barriers between potential service providers and individuals in need of this service. Location and lack of transportation may also prevent access. Continuity and quality of service issues are created so, from a consumer perspective, the labor market may not meet standards.

 Unavailability and unaffordability of personal care assistants may result in other services being used to meet only part of the need. Some persons with sensory disabilities are not able to access subsidies to pay for personal assistance needs (IADL's).

Home health aides may meet some service needs, but may not fix meals. Other providers or volunteers through AAA, scouts, or churches may be needed for minor home maintenance, upkeep, and chores such as mowing lawns, cleaning windows, snow removal, and leaf and trash removal.

## **Assistive Technology - GAPS**

## <u>Description</u> - Areas where gaps have been identified include:

- -Durable Medical Equipment (wheelchairs, walkers, bedrails, dialysis equipment, portable commodes, etc.)
- -Communications equipment (TTY, computer with online access, video readers, etc.)
- -Emergency Alert Services
- -Environmental Control Units.

There are gaps of affordability, accessibility and acceptability for these assistive devices.

- Rapid changes in technology lead to a knowledge gap among providers and potential users around what are the best and most helpful products available to assist them. It is difficult for care providers to stay abreast of current technological advances, and even more challenging for individuals needing services and devices.
- There is a general lack of awareness of what products and services are covered by insurance or available through community resources. One community loan closet provider estimates that at least 3 of the 12 calls he receives each day are from those who were not aware that they qualify for coverage for their medical equipment through Medicare, Medicaid, or Veterans benefits.
- Although there are still psychological and attitudinal barriers that make assistive devices unacceptable for some persons, research has noted some positive trends.

National surveys in both the U.S. and Canada consistently demonstrate a trend toward an increase in use of assistive devices and decline in the use of personal assistance by older people with varying levels of functional disability and impairment. People with visual impairments tend to report higher use rates, while those with cognitive impairments report the least number of devices. During the first month home, 47 percent of the assistive devices issued were being used on a regular basis. If a person is eligible for Medicaid or Medicare, then many assistive devices are covered, including a range of durable medical equipment. There are gaps in this coverage, however.

For example, Medicare does not pay for bedside commodes, but Medicaid does. If a person is middle income and does not have long-term care insurance that covers these items, then it is very costly and the best assistive technology may not be affordable. For example, a standard wheelchair costs between \$400-600 while a motorized wheelchair can cost \$1,300. Private insurance may cover less than 50 percent of these items. For a low-income disabled person, the balance may represent 25 percent of their income. TTY prices range from a basic model for \$150 to \$700 for a computer compatible model.

- Few distributors and providers of durable medical equipment and assistive technology are located locally, creating an accessibility gap. Equipment often must be sent out of state for repair. Replacement parts may be difficult to obtain, as is loaner equipment to cover the need during the repair time.
- Demand for assistive technology including durable medical equipment is increasing due to the increasing population of persons who are disabled and to the increased use of assistance devices in lieu of personal assistance. National and regional surveys found that older persons indicate that they have a need for additional equipment and technology to help with a wide range of problems. In one study, older respondents who had been discharged from rehabilitation to their homes, received an average of eight devices. Feedback from local equipment loan closets indicated an average of four devices loaned to each family. Of 8,000 families served by the Washington Wheelchair Society, 32 percent were from Northern Virginia (2,560) and their demand is up sharply in recent years.
- Computers with online access provide a wide range of assistance including information about services, social contact through email and online support groups,

accessible options for bill-paying, banking, and applying for services. The Washington Metro area is listed in the top five most wired metropolitan areas in the country, with Internet penetration to 56 percent of the households. However, a "digital divide" prevents many low-income persons and some minority populations from accessing these services. Nationwide, computer ownership by blacks increased 125 percent from 1994-98, while ownership among Hispanics grew 42 percent. Less than half of the country's Latino population owns a PC or has Internet access at home.

• Many technological adaptations that would allow a person with a disability to perform comparably to other employees can be made at no cost (20 percent) or moderate cost of less than \$1,000 (60 percent). Equipment such as screen magnifiers, Braille writers, and voice recognition software make it possible for the disabled to access the Internet to find job listings, and also to produce resumes and cover letters. Lack of awareness of these resources, as well as financial limitations, often prevent the disabled from acquiring and utilizing these tools which would help them both at home and with employment.

## **Psycho-Social Supports - GAPS**

<u>Description</u> - Social infrastructure, peer and family support, spiritual support and nurture, psychological assessment and services, volunteer friendly visitors/companions, and psychiatric services available in the home. Feedback from recent County Long-Term Care customer surveys emphasizes the value that clients place on the companionship and the need for psycho-social supports.

- A recent White House report on Older Adults and Mental Health estimated that an unmet need for mental health services may be experienced by up to 63 percent of adults aged 65 and above.
- Attitudinal barriers and lack of understanding prevents many elderly and disabled persons and their caregivers from identifying and seeking assistance for mental health issues. Recent studies indicate that incidence of mental health disorders among the elderly is underestimated by at least 25 percent, with assessed prevalence of non-dementia mental illnesses at 16.3 percent among elderly persons. Additionally, 10 percent of elderly persons have dementia, usually Alzheimer's. Patients tend to emphasize medical illnesses in visits to physicians and are reluctant to disclose psychological symptoms.
- Primary care providers are often unfamiliar with the manifestations of mental illness and psychological disorders. One study of primary care physicians revealed that only 55 percent of the internists felt confident diagnosing depression, even fewer with treating the elderly for depression. Diagnosis is complicated by co-existence with other medical disorders that may mask the condition. These missed diagnoses create an accessibility gap for patients and families who may be suffering from depressive symptoms.
- Assessment and diagnosis of late-life mental disorders are especially challenging because the clinical presentation varies in older adults. While 20 percent of elderly patients present with some symptoms of depression, only 3 percent meet the criteria for treatable major depression, creating both affordability and availability gaps.

- Hearing loss in older adults frequently results in social withdrawal and isolation which increases the risk of depression. More than one third of the non-institutionalized elderly suffer from significant hearing loss. Communication difficulties may cause friends and family to withdraw or limit contact with the affected person, and social interaction with volunteer visitors may increase frustration. Coping strategies for preventing or dealing with depression, such as talking with friends or a counselor, may be ineffective.
- The most serious consequence and telling indicator of undiagnosed and untreated depression late in life is suicide. Older persons (65+) have the highest suicide rate of any age group and the suicide rate for persons age 85+ is about 21 suicides per 100,000, over twice the national average. Trends from 1980-92 indicate that suicide rates are increasing among elderly persons.
- There is presently a shortage of affordable mental health providers including those that accept Medicare or Medicaid. Consequently, there are waiting lists for outpatient mental health services at community health centers and there may be wait lists of 4-8 weeks for a medication appointment with a doctor, and for in-home counseling and therapy. These shortages create gaps in affordability.
- Even when insurance coverage is available, there may be a gap of acceptability as many older people are not comfortable with traditional mental health settings and prefer to receive treatment for mental disorders through their primary care physicians. New models are being developed for delivering psycho-social interventions in the primary care setting.
- Psycho-social assessment is supposed to be part of assessment for in-home services through the Medicaid Waiver (UAI scores on cognitive/social needs).
   Community Services Board Mental Health Services has no waiting list for mental health assessment. However, if assessment indicates a need for treatment, there are often long waiting lists, creating an availability gap.
- For patients with Medicare or private insurance, there are visiting psychiatric nurses.
   The co-pay for Medicare and many other insurers is 50 percent for mental health services, and the number of visits is limited.
- Language and cultural barriers may limit the ability of the health professionals to diagnose mental health needs and the ability of the home care provider to provide psycho-social support.
- Access to support networks and psycho-social contacts assume heightened importance for older persons living alone, as they are often uncomfortable with formal mental health services. Support groups that address the specific issues and concerns of aging such as bereavement, loss of independence, and isolation have been shown to be especially effective with participants exhibiting fewer depressive symptoms and an increase in new relationships.
- Various community organizations provide volunteers to visit with elderly and disabled home-bound persons. Community Friend volunteers provide companionship to 60 individuals. The Friendly Phone Visitor and Reassurance Program provides

companionship through volunteers to 80 individuals. Interfaith Volunteer Caregivers provides a range of assistance and companionship to 120 families. There are inadequate volunteers to meet the demand for friendly visitors, and a number of providers have waiting lists. Fewer friendly visitors services are available for the disabled adults. There is also of shortage of visitors to serve the multi-lingual population.

Medicaid will pay for in-home assessment of the patient's therapeutic recreation needs. In addition, Medicaid will pay for participation in some forms of recreation services to foster improved psycho-social outcomes. For these types of services, the person generally goes to the recreation activity outside of the home.

## **Financial Supports -GAPS**

<u>Description</u> - This includes in home assistance with bill paying, banking, tax preparation, budgeting and planning, as well as eligibility determination.

- Bill paying and Banking Some assistance for these needs is available through case management or may be provided by a personal assistant. When that is not available, there are some volunteer organizations that may provide these services through friendly visitors, but there are waiting lists.
- Cognitive Services GAPS Tax Preparation assistance is provided to seniors by volunteers through VITA as well as by AARP. This service is generally provided at a central location, though in very limited cases volunteers may go to the home.
- Budgeting and Planning Services are provided through Brain Injury Services, though presently there is a waiting list of more than 50.
- Eligibility determination and assistance is provided to persons with mental disabilities, and some Medicaid recipients, in applying and qualifying for Federal benefits through Legal Services of Northern Virginia. Through the Virginia Insurance Counseling & Assistance Program, the County provides advice to residents on assessment of eligibility, insurance coverage, and assistance with benefit appeals. In 1999, they provided services to 807 individuals, an increase from 655 in 1997.

<u>Description</u> - Cognitive Services are provided to people who have a limited or impaired ability to process necessary information sufficiently to care for themselves independently. The disability may be due to developmental disabilities, mental retardation, or brain injury. There is wide variation in the degree of impairment and on the types of assistance needed. Impairments may include loss of memory, lack of concentration, slowed ability to process information, or inability to sequence tasks or activities to conduct daily living or manage personal affairs. Persons with acquired brain injury can also experience loss of their sense of self and can be affected physically and emotionally as well as cognitively. There are substantial gaps in Availability and Accessibility of cognitive services.

 The availability of cognitive service is limited for residents of Fairfax County. In some states, Medicaid provides cognitive services to support in-home functioning. In Fairfax County, cognitive services are accessible with Medicaid eligibility for the targeted populations of persons with mental illness, mental retardation, or serious developmental disabilities. The Alzheimer's Association does not provide in-home cognitive services.

- There may be a larger gap for ongoing assistance than for the purpose of training someone who is recovering from brain injury (due to stroke or trauma). There may also be training and labor supply gaps that limit the availability of this service.
- People who have significant learning disabilities, but not mental retardation or brain injury, are not eligible for current programs, and are thus locked out of services that might otherwise be available.
- The size of the population in need of cognitive services in Fairfax County is not well defined. The Fairfax CSB reported 501 adults with mental retardation in need of residential services as of June 1, 1999, with 40 percent of those living with a caregiver age 60 or older. Cognitive services would be part of the services needed for this population. Nationally, about 2 percent of people are living with disabilities resulting from brain injury, and the Center for Disease Control estimates about 1,400 individuals with disabilities resulting from brain injury live in Fairfax County. However, not all of these persons would need cognitive services.

# APPENDIX A4: Supports to Families Committee Report

The American Society on Aging (ASA) reports research showing that caring for older people often exacts a heavy emotional, physical, and financial toll on the caregiver. This research is corroborated by a member survey conducted by the National Family Caregivers Association in 1997. Caregivers experience a sense of burden, and may become depressed, angry or anxious, which may increase as the care recipient's condition deteriorates.

The majority of caregivers are themselves over 50 and may be at risk of health problems, which can be precipitated or aggravated by the physical strain involved in heavy lifting, bedding changes, dressing, bathing and toileting another adult.

Caring for another may also have a financial impact on the caregiver in several ways. An estimated 28 percent of caregivers quit work in order to provide care, reducing both their current and future potential income. Those who do work outside the home may experience reduced effectiveness on the job, and worries over paying for long-term care can add to their emotional distress. The incidence of poverty and near-poverty among caregiver families is higher (about one-third) than among same-age families with no caregiving responsibilities.

The committee looked at services and supports that focus on the overall well being of families who are caring for a person in need of long-term care such as respite care, case management, financial, legal, and employment concerns as well as faith-based spiritual support.

#### **Definitions**

## Financial/Legal/Employment

These services enable caregivers to effectively plan and manage the financial, legal, and career needs of themselves and family members while balancing these components with their other responsibilities. Areas of focus will include: insurance (long-term care, life, and health); estate planning; living wills; legal rights of caregivers; Family & Medical Leave Act; employer discrimination; and employment services (potential effects on training, advancement, and promotional opportunities, flexible work hours and venue).

### **Case Management**

The ability and resources of the caregiver to manage and/or oversee the care of a person who is unable to make their own decisions. Areas of focus include information and services provided by commercial, governmental, and independent sectors.

## Psycho-Social/Physical

These services meet the psychological, social, and physical needs of families. Areas of focus include psychological change indicators; relationships with other family members; self fulfillment of social/recreational needs; interaction/advocacy with medical community; and understanding the implications of being a long-term caregiver.

#### **Respite Care**

Planned care or activities with a purposeful benefit of giving the primary caregiver significant relief. Areas of focus include:

- location (site based, home based, other program or activity based day, recreation);
- duration (less than one day, overnight, multiple days); regularity (structured regular, predictable, scheduled; intermittent irregular, known in advance; emergency)
- level of care (companionship, light supervision, IADLs; higher level of dependence bathing, feeding, toileting, dressing, and medically – behaviorally complex.

## **Spiritual**

Services provided by faith-based organizations. Areas of focus include spiritual counseling, home religious services, information regarding end of life decisions, and referral sources for religious/faith-based social services.

#### <u>Themes</u>

- Services to support caregivers are provided in our community at a variety of cost structures.
- Information regarding specific services and supports are not widely known by caregivers.
- Although the trend of employer-sponsored LTC insurance is going up, there continues to be an availability gap for most of the workforce.
- The emphasis is on what the family needs to support the individual with long-term care needs, and what the family needs to support itself as the caregiving family.
- Families need a spectrum of help from simple information to education, to training, to direct services.
- Government does not play a major role in supporting caregiving families, either in terms of funding or services.
- Primary sources of support for families are disease or condition-specific advocacy organizations, support groups, and physicians.

#### Gaps

## Financial/Legal/Employment Services

Long-Term Care Insurance is expensive and not accessible to most families.

Because long-term care (LTC) insurance policies are complicated and relatively expensive, particularly when purchased late in life, it has been difficult to sell large numbers of them. Only about six million policies are in force and, so far, less that 10 percent of the nation's elderly has purchased long-term care insurance, according to the American Council of Life Insurers (ACLI). The cost of comprehensive coverage depends on how old you are when you buy LTC insurance.

In general, the earlier a policy is purchased, the lower the premiums. However, people must weigh the lower cost against the fact that they will pay the premiums for a longer period before they are likely to need the type of help the policy is designed to provide.

A new ACLI study shows that a 55-year-old would pay \$911 a year for LTC insurance that pays \$100 a day for three years of assistance in the home or community, or that pays the same benefit for three years of care in an assisted-living

or nursing-home facility. (It also includes 5 percent inflation protection, compounded annually.) A 65-year-old would pay more than double that amount - \$1,830 a year – for the same coverage and a 75-year-old could find themselves paying anywhere between \$2,805 - \$3,895 for the same coverage (5 percent noncompounded for age 75).

 An accessibility gap exists for some elderly Americans wanting to purchase LTC insurance based on new research from the Agency for Health Care Policy and Research (AHCPR).

The research indicates that under current medical underwriting practices, between 12 – 23 percent of Americans would be rejected if they applied for LTC insurance at age 65. These figures rise to between 20 – 31 percent at age 75 according to a study by researchers from the AHCPR Center for Cost and Financing Studies. Based on these criteria, the study simulates probable exclusion of persons who are current or recent nursing home residents, are unable to perform basic ADLs, have cognitive disabilities such as Alzheimer's disease or other forms of dementia, or major illnesses such as cancer, cirrhosis of the liver, long-term diabetes, or chronic obstructive pulmonary disease. \* (Source: "Risky Business: Long-Term Care Insurance Underwriting," by Drs. Murtaugh, Kemper, and Spillman, in the Fall 1995 issue of Inquiry 32, pp. 271-284.)

Although the trend of employer-sponsored LTC insurance is going up, there continues to be an availability gap for most of the workforce. Employer-sponsored group LTC insurance sales were up 126 percent in 1999 and in-force sales were up 24 percent. Over the decade, there has been a gradual drop in the size of the average employer group buying LTC insurance. Large employers seemed to be the earliest offerers (At&T, IBM, Ford Motors, American Express, Monsanto, Proctor & Gamble, the World Bank). In 1994 the average size of an in-force U.S. employer group product was 434 employees. By 1998, it was down to 268.

According to the Bureau of Labor Statistics, only 7 percent of full-time employees in medium-size to large private businesses were offered long-term care insurance as a voluntary benefit in 1997. This statistic does not include the employees whose employers subsidize their long-term care benefits. Although those plans are not as prevalent as voluntary plans, they continue to show growth through annual open enrollments – particularly among affinity groups such as teachers' organizations.

There is a large information gap surrounding the public misperception that the government Medicare program provides an overall safety net for Americans when they reach the age of eligibility. However, Medicare, with its focus on acute care, not chronic care, is not designed to cover long-term care expenses. And since long-term care insurance had its origins in the skilled nursing facility benefits, it has come to be identified as nursing-home coverage, whereas today's plans also provide options for many other benefits such as assisted living, home care, respite care for the insured's caregiving spouse and even informal caregiving training. Chronically ill people want to receive care in their homes and from family caregivers as long as possible, and long-term care policies allow this to happen.

Under the recently enacted federal health insurance legislation, know as the Kennedy-Kassebaum bill, long-term care insurance premiums incurred after

December 31, 1996, are now deductible as medical expenses, up to a limit that varies by age. However, with so few older people able to purchase such insurance, this tax break will benefit very few.

Legislative proposals to encourage expansion of private long-term care insurance plans include a tax credit to individuals for purchase of a private long-term care policy or to employers for subsidization of group long-term care insurance plans. Under consideration by Congress are proposals to encourage enrollment in long-term care insurance plans by federal employees. (Source: National Aging Information Center, www.aoa.dhhs.gov/naic/)

The Area Agency on Aging's Virginia Insurance Counseling and Assistance Program (VICAP) educates, counsels, and assists older consumers on medical benefit programs, long-term care insurance, and problems with Medicare, Medicaid, and medical bill paying

Estate Planning is often complicated and confusing to families who may perceive this service as being only for the wealthy due to the limited availability gap of information in this area. Legal and financial planning are key services to help families plan for the costs of future long-term care and to make arrangements for medical decisions and advance directives. Cognitive impairment, in particular, creates complex legal and financial problems for impaired persons and their families, who may need advice on property rights, contracts, estate planning methods, durable powers of attorney, and other matters.

Frank Johns, president of the National Academy of Elder Law Attorneys, regularly encounters clients who seek advice only after having spent just about everything. If families were aware of their legal options, the situation could have been better managed. With the decriminalization of Medicaid planning, elder-law attorneys are free to help clients qualify for Medicaid while retaining as many of their assets as the law allows. (Source: Kiplinger's March 2000 article; "Knowing the Score" by Mary Beth Franklin, http://www.kiplinger.com/)

- Living Wills: There is an information availability gap associated with knowing the importance and basics of writing a living will. Living wills are often an uncomfortable topic for folks to address given the saddened state of affairs when wishes outlined by the person move into reality.
- Legal rights of caregivers around information regarding the Family Medical Leave Act (FMLA) poses a gap in understanding for families as well as employers. The specific criteria and fine points of the law are not widely known and therefore limit folks from accessing this benefit. In addition, the law may protect a family caregiver's job security but it does not address the issue of lost income.

FMLA of 1993 was an important first step to help protect the jobs and work benefits of employees who also have family care responsibilities. The law permits full-time employees to take up to 12 weeks of unpaid leave per year for a birth, adoption or care for an ill child, spouse or parent. The law provides unpaid leave; however, for family caregivers who cannot afford lost income, the time off may not meet their real needs. The law covers only about 11 percent of American worksites and 60 percent

of American workers; those who work in small businesses are not covered by the federal law. Workers caring for an aunt or uncle, a sibling, a grandparent, or an unmarried partner also are not covered.

Tax Incentives: There is an information gap regarding the specific criteria that enables families to use these tax strategies – tax credits and tax deductions. Tax incentives are available in the form of adjustments to gross income or itemized deductions from taxable income for families who are caring for a chronically ill individual.

Beginning in 1997, out-of-pocket expenses for long-term care, including custodial care and long-term care insurance premiums, are deductible as medical expenses. The expenses must be for care for a "chronically ill individual" who needs help with at least two activities of daily living or requires "substantial supervision to protect against threats to health and safety due to severe cognitive impairment. Tax deductions tend to favor higher income people, giving them more subsidy per dollar deducted.

Tax credits generally benefit low-income taxpayers and require the caregiver to live with the care recipient and be employed outside the home. These requirements tend to limit the use of this tax strategy, particularly when one family member – usually the female spouse – has the full-time job of caregiving.

### **Respite Care**

In-home respite care can be costly for families needing assistance beyond a period of a few hours, creating an affordability gap.

1998 County Household Survey data shows that persons with disabilities are more likely to live in low-income households than persons without disabilities. For example, 31 percent of the persons over 65 who have disabilities live in households with annual incomes of \$25,000 or less. With prices in the \$15 to \$17 per hour range for companies and \$8 to \$15 per hour range for individuals, extended respite care service is not affordable for many households.

Center-based respite care, which is frequently offered by nursing and assisted living facilities, can range from \$150 to \$190 per day, depending on the client's need and the center based accommodations. Again, this can be beyond the means of some Fairfax County households.

Staff supporting the Committee canvassed respite care providers, but insufficient data was collected to determine if there are availability gaps. The providers canvassed did not express difficulties in meeting requests for respite care, but the number was too small to make any County-wide assumptions. The same is true for data about labor supply issues in the provision of respite care. The Committee recommends continued data collection to more definitively determine availability and acceptability gaps for the following areas associated with paid respite care.

 Location: site-based, home-based, program-based. There is an availability gap associated with site and home-based respite care for some areas of Fairfax County.

- Duration: hourly, daily, weekly.
- Regularity: scheduled/predictable, intermittent/irregular, emergency.
- Level of Care: IADL's (light supervision, shopping, companionship).
- Level of Care: ADL's (bathing, feeding, dressing; medically or behaviorally complex).

Demographic and social trends will affect family care in the future. Long-term care costs may more than double in the next 25 years. At the same time, the population is rapidly aging, and the American family is changing. By 2030, when the baby boomers reach age 65, approximately one in five Americans will be at least 65 – or about 70 million older people, more than twice their number in 1995.

Not only is the older population increasing, but it is living longer. In 1996, people reaching age 65 had an average life expectancy of an additional 17.7 years (19.2 years for females and 15.5 years for males). By 2040 there will be almost four times as many people over 85 as there are today. As the population ages, the number of people with chronic conditions requiring long-term care will increase. Over the next 25 years, the number of people with chronic impairments is estimated to increase by 35 million people to 134 million Americans. \* (Source: American Society on Aging Family Caregiving Report)

Five social trends may affect the supply of caregivers in the future: increasing divorce and remarriage rates; increasing geographic mobility; decreasing family size; delayed childbearing; and more women in the workplace.

In Fairfax County, the high percentage of women in the labor force (over 73 percent in 1998, compared to 60 percent nationally) constrains the availability of women as possible caregivers for family members. This situation may add to the demand for paid caregivers, but simultaneously limits the number of potential caregivers, contributing to labor supply issues for home care in the County. The overall high labor force participation rate in the County for men and women, nearly 79 percent compared to 67 percent nationally, also contributes to the labor supply shortage for home and personal care providers. The ASA reports that, nationally, between one-third and two-thirds of caregivers are also employed outside the home.

A Caregiver Member survey was conducted by the National Family Caregivers Association (NFCA) in 1997, providing us with a profile of caregivers across the country. Eighty-two percent of caregivers are female and have been providing home care for at least 5 years up to over 15 years. Seventy-four percent of caregivers are married with 36 percent between the ages of 51 – 65 years old, and 34 percent between the ages of 36 – 50 years old. The majority of these women are caring for their spouse (48 percent), or parent (24 percent). In addition to their caregiving responsibilities, almost half (47 percent) are employed outside of the home. Of those employed outside of the home, 71 percent work full-time (more than 31 hours/week).

### **Case Management**

# Family caregivers need training and support to learn how to become their own case managers.

- Information and services provided by the government are not widely known to families. Services, education, and training regarding case management is a knowledge gap for families, thus limiting their ability to access services that do exist. Eligibility criteria for accessing case management services also varies among service areas and may be limited to serving low income individuals.
- Help with advocacy and interacting with the medical community is a big gap when it comes to the family caregiver's ability and confidence in knowing how to deal with the medical community. People need to know that they can and must advocate for their family members.
- Information and services provided by the commercial sector poses an affordability and availability gap. Medical professionals offer case management to some degree, but their availability to provide such support will continue to diminish as the healthcare industry becomes more commercialized.
- Information and services provided by the independent sector or non-profit organization poses an affordability and accessibility gap for caregivers. Given the population demographics, the need for community-based case management services will significantly increase in the next 10 years. Knowing where to go for quality services at a lower cost than commercial operations will be a huge factor.
- The definition of Case Management varies among disciplines within both the public and private sectors. What may be a long-term discrete service in one area can be a short-term training and support service in another. This results in a gap in understanding among professionals and confusion among family caregivers in what to expect.

# **Spiritual**

- Spiritual Counseling is not a gap in itself; however, there may be a need for cross learning between long-term care providers and the faith community.
- Home Religious Services may pose an availability gap for full services directly in the home.
- Information regarding end of life decisions is an acceptability gap and possibly an
  accessibility gap in terms of where to find information that is valid and in the best
  interest of the person in need of care.
- Information and referral resources for faith-based social services are not widely known to area residents.
- Caregiver Supports: While faith communities are a source of assistance for caregivers, they do not appear to be organized around supporting family caregivers.

The Faith in Action Coalition produces a directory of services provided by Faith groups; however, there is no section on Caregiving.

# Psycho-Social/Physical

- Psychological services -- individual and group counseling: While there does not appear to be an affordability gap, there is an accessibility gap for those individuals/families without transportation living in outlying areas of the County.
- Support groups: There is an awareness gap for caregivers not knowing where to go look for supports.

There is clearly not a gap in the number and variety of support groups and internet sites for family caregivers, although there may be a local gap in support groups for some specific conditions. The Family Caregiver Alliance and the Caregiver.com websites offer online chat rooms for caregivers, a listing of over 200 specialized illness/disability specific support groups, and direct links to hundreds of other websites that offer supports and services to caregiving families.

Overall Health & Well Being: There is an awareness gap that is associated with the physical and mental health risks to family caregiving. The ASA reports research showing that caring for older people often exacts a heavy emotional, physical, and financial toll on the caregiver. This research is corroborated by a member survey conducted by the National Family Caregivers Association in 1997. Caregivers experience a sense of burden, and may become depressed, angry, or anxious, which may increase as the care recipient's condition deteriorates. The majority of caregivers are themselves over 50 and may be at risk of health problems. In addition to increased headaches, stomach disorders, back pain, sleeplessness, and depression, studies also show that caregivers have lowered immune function and nearly double the normal use of psychotropic drugs.

There is also a study that has documented an increased mortality rate among caregivers. Caregivers often find themselves feeling a sense of isolation and lack of understanding from others. They are stressed by having the responsibility for making major life decisions for a loved one while having no consistent help from other family members.

# APPENDIX A5: Transportation Committee Report

### **Themes**

# Recurrent themes identified for transportation services are:

Mobility is a critical issue in maintaining a level of independence, preventing isolation and permitting the elderly and persons with disabilities to continue to make contributions to the community.

The private automobile is, and will continue to be, the single most important mode of transportation for seniors. There will be a dramatic growth in senior drivers. Not enough is done to facilitate "senior driving."

Pedestrian transport is also a critically important mode of mobility for the elderly and persons with disabilities. Fairfax is not a particularly pedestrian friendly community.

There is inadequate capacity in our paratransit resources.

There is a lack of cohesion and very little coordination between and among the various fixed-route and paratransit services available in the County. There is no systematic method for determining how many disabled and elderly are in need of transportation services. Nor is there a systematic approach for coordinating the utilization of the various transportation services. Paratransit systems in Fairfax do not readily interface with the fixed route transportation system in an efficient manner.

Land use planning has not been used as much as possible to facilitate mobility for seniors and persons with disabilities.

County transportation services for the disabled and elderly are restrictive and inflexible. FASTRAN services are limited with respect to income levels, hours of operation, and specific service focus. Overall transportation services are not well oriented to the needs of individuals but instead are more program focused. Fixed route transportation is geared to rush hour commutes, not daily tasks and non-commutation activities. The paratransit system operates on a limited schedule, and is not flexibly geared to daily tasks and/or evening activities.

There is no same day service in the paratransit system. Non-program related transportation is largely limited to the hours of 10:00 a.m. to 2:00 p.m.

Eligibility criteria for various transportation services are unclear, duplicative, and burdensome. Seniors have difficulty understanding program eligibility criteria.

The multi-cultural dimension of the Fairfax community has a significant impact on the transportation system supporting long-term care clients. Persons whose primary language is not English face language barriers and, at times, literacy barriers as well. This affects their ability to locate, understand, and use transportation resources. In addition to not being able to understand what public and paratransit services are available, senior adults from other cultures may not have had a driving or public transportation experience in their native country. Even some native Americans

experience a culture shock when confronted with the need to use public and/or paratransit services for the first time.

There is little support to help seniors and persons with disabilities with "mobility transition planning," that is, learning how and preparing to use new modes of transportation.

There is a broad-based awareness gap regarding transportation services. The marketing of these services is inadequate and does not reach individuals in need of service. Seniors have a difficult time determining what transportation services are available. Most promotional materials for transportation services are in English only.

Private transit services such as taxicabs are far too costly for seniors and the disabled to use on a routine basis.

#### **Private Automobile**

Fairfax County residents, like other suburbanites, have achieved personal mobility independence through the use of automotive travel. For many individuals with long-term care service needs, the private automobile is still the primary mode of transportation available.

Nationally, according to a 1999 study entitled *Mobility and Independence: Changes and Challenges for Older Drivers*, conducted for the U.S. Department of Health and Human Services and the National Highway Traffic Safety Administration, the numbers of older drivers -- people 65 and older, 75 and older, and 85 and older -- can be expected to increase substantially, at least doubling. Older women are expected to drive in greater proportions than is now the case. The number of drivers age 85 and over in 2030 will be four to five times greater than today.

Generally car trips diminish as age increases. The 1990 Nationwide Personal Transportation Survey showed that by the time an individual reaches 75 years of age, trip making had diminished considerably. According to the survey, 63 percent avoid driving at night. Fifty-one percent avoid driving during rush hours. Among older persons who discontinued driving within the last three years, 61 percent stopped due to physical impairment. Other reasons provided for discontinuation of driving include the inability to afford a car, not having a need to drive, and getting rides from a spouse/others.

However, despite this overall trend the 1999 HHS/NHTSA study indicates that older drivers are driving more (taking more trips and driving more miles) than before. Between 1990 and 2020, the total annual mileage driven by older male drivers will increase by 465 percent -- and this estimate is conservative. For elderly female drivers, the total annual vehicle miles driven will increase almost 500 percent (again, based on conservative estimates). By 2030, according to these conservative estimates, elderly drivers will account for 18.9 percent of all vehicle miles driven, almost triple the 1990 figure.

Available local data indicates that senior driving is prevalent and may increase more dramatically than the national data indicates. Based on the 1998 Household Survey, 99.6 percent of householders aged 60 and older had at least one car and 61.6 percent reported that they had two or more cars. Nationally, according to a 1997 AARP study, one-fourth of the 75+ group do not drive and this number is expected to increase.

However, locally (among the 75+ age cohort of the Household Survey), less than one-half of 1 percent reported that they <u>didn't</u> have at least one car and almost half of this age group had two or more cars!

The automobile remains the centerpiece of mobility for many with long-term care needs. This has significant implications for transportation planning. It requires that we simultaneously pay attention to strategies to help make driving as safe and comfortable as possible for the elderly while at the same time having the resources to meet mobility needs when driving must stop. It also means that individuals should be encouraged to plan non-automobile based mobility strategies early on, rather than waiting until all driving is no longer an option for that individual.

#### **Gaps: Private Automobile**

- Affordability- Owning an automobile is expensive, especially if one drives infrequently and drives short distances.
- Accessibility- Aging processes affect individuals in many ways, resulting in a broad range of capabilities and extensive differences among older individuals. The increased incidences of disease and decline in capacities that are part of the aging process generally impair the cognitive, sensory, or psychomotor capacities needed for the operation of all transportation vehicles. This can create safety issues.
- At present, there are not a sufficient number of crashes associated with older users and operators to be identified as a serious safety problem. However, changing demographics could lead to more serious problems in the future. The safety problem is an issue when the crash and fatality rates per mile driven are evaluated. The fatality rate per 100 million vehicle miles traveled stays reasonably level for drivers up to age 75, and then begins to rise, climbing steeply for persons over 80. A higher fatality rate for those over 80 is partly attributable to their greater fragility compared with younger persons.
- Accessibility- Most individuals, as their capacities diminish, gradually withdraw from operating an automobile. In the 1990 Nationwide Personal Transportation Survey, 30 percent of the individuals surveyed reported that they felt uncomfortable with specific physical design aspects of roads and/or traffic situations they encounter. They avoid interstate highways, heavy traffic areas, and rush hour. This further constrains mobility.

#### **Pedestrian Transport**

For those that are able, walking (or using a wheelchair), in a person's immediate community, can meet a tremendous amount of mobility needs when the infrastructure and the design of the community is supportive of pedestrian transport. Walking is often the vital transportation link to the mass transit system.

#### **Gaps: Pedestrian Transport**

 Accessibility- There are several factors which contribute to the accessibility gap for pedestrian transportation. Fairfax County, like many suburban communities, is not "walking friendly." Suburban development is not often geared to walkers. It is, more often than not, in most areas of the County, impossible to reach shopping, medical, and other services by walking. Often it is difficult to reach public transit by walking. Inadequate sidewalks and the grade of sidewalks in older communities are significant issues.

Lack of sitting areas along pedestrian trails also presents a problem for individuals who may be carrying or pushing items, using quadpod canes, walkers, or wheelchairs. According to the Fairfax Area Disability Service Board 2000 Needs Assessment, "inadequate sidewalks are a major accessibility and safety issue...People are often forced into dangerous situations just to try and get to bus stops or directly to their destinations."

 Accessibility and Acceptability- The majority of intersections have no means of control for pedestrians wishing to cross the street.

Mobility impaired pedestrians, who are slower-moving, fear for their lives as they cross the street as drivers turn right on red. Right-turn-on-red is a hazard to visually impaired pedestrians. In addition, the walking speed for older adults is less than the Manual on Uniform Traffic Control Devises (MUTCD) suggests, which is four feet per second as a normal walking speed. Older adults walking speed puts them at risk of being injured or killed.

The risk of dying in a pedestrian crash increases with age. Pedestrians, 65 and older, are two to eight times more likely to die than younger persons are when struck by motor vehicles. Individuals over 65 account for only 12 percent of the population but are 23 percent of pedestrian fatalities. Population shifts indicates that this is a growing problem. Older pedestrians, compared to other age groups, face higher crash and fatality rates at intersections.

#### **Fixed Route Transportation**

Fixed route transportation services in Fairfax County (Metro, Cue, RIBS, Connector, etc.), while an invaluable service to our community, present significant gaps as transportation resources for long-term care consumers.

Metro is part of the Washington Metropolitan Area Transit Authority, which consists of the Metrobus and the MetroRail. Metrobus operates many bus routes in Fairfax County in areas such as Centreville, Chantilly, Fair Oaks, Annandale, Bailey's Crossroads, Seven Corners, Tysons Corner, Alexandria, Fort Belvoir and Springfield. Almost all Metrobus routes connect with the MetroRail stations, which are limited. The transit system is designed primarily to support commuting to and from Washington D. C. It is often not an effective means of transportation for individuals traveling across the County.

Metro does provide reduced fares for seniors and individuals with a disability carrying special identification cards. Lift-equipped and kneeling buses make up more than 70 percent of the fleet. The buses are equipped with platforms that lower to the curb and lift the passenger in a wheelchair, on board. Once on board, the wheelchair is secured in a reserved area. According to Metro, regularly scheduled lift service is available on most routes. On others, only some trips (identified on the schedule) are lift-equipped. If lift-equipped buses are not available on a rider's route, he/she may use On-Call Service.

This service provides a lift-equipped bus from one Metrobus stop to another with advance reservation. On-Call Service is available seven days a week on a first-come, first-served basis. Registration is not required.

Generally, fares on metro buses are \$1.10 on regular routes. The senior and disabled fare is 50 cents and is valid on all routes at all times for senior citizens 65 years of age and older and for people with disabilities. One must show a WMATA ID or Medicare card.

The Fairfax City CUE Bus (City University Energy-saver) is another fixed route system. The system is designed to serve the needs of city residents and George Mason University students. CUE buses stop throughout the city along main roads, at the university, and at all major shopping and recreation areas. CUE buses also provide transportation to the Vienna MetroRail station. Fares are 50 cents, with discounts for seniors and school students. During weekdays, there are four buses running on the Green Line and four buses running on the Gold Line. On the Green Line, two buses run clockwise -- Green 1, and two buses run counter clockwise -- Green 2. The same is true for the Gold Line. They operate seven days a week and service begins as early as 6:00 a.m. and ends as late as 11:30 p.m., depending on the destination. There are handicap-accessible buses on every route.

The Fairfax Connector is the County's Transit Bus System. It includes three divisions of bus services, Huntington, Reston-Herndon, and Community Bus Services. The service is designed to get individuals to the Metro. The hours are based on a commuter schedule and, therefore, have limited hours of operation and routes. There are few mid-day hours of operation.

#### **Gaps: Fixed Route Transportation Services**

- Accessibility-There is a fragmented service structure among fixed route providers
  that constrain their use by the elderly and persons with disabilities. They are not well
  linked in terms of route connectivity or from the standpoint of providing information
  on how one system may be used to access another system.
- Accessibility- Persons with impaired mobility often cannot get to fixed route transportation stops. Those that are physically able to access public fixed route transit can be discouraged from doing so because there is limited pedestrian friendly access (paths, sidewalks, trails) to transit stops. In addition, the absence of bus shelters, poor lighting, and failure to clear snow and mud from access routes and stops present barriers to using public transit. This is significant because the 1998 Fairfax County Household Survey revealed that persons, aged 21-60, with a physical or sensory disability were much more likely to be users of public transportation (16 percent) than those without a disability (9 percent) as their means of travel to work.
- Accessibility- Fixed route service times are often restricted. They are geared to commutiing and often do not support daytime chore-related transportation or social or civic activities in the daytime or evening.

- Accessibility- There are language and experiential barriers for elderly and disabled persons from other cultures to using fixed route transit services.
- Availability There are gaps in areas covered by fixed route systems. Persons with disabilities that are able to work but do not have access to private transportation find it difficult or impossible to obtain or retain employment. The service area gap, particularly severe in the western and southern areas of the County, also impact the ability of relatively low-wage professional care givers to get to potential clients. Both groups are often forced to make more costly housing choices in order to be near transportation.
- Availability- There is a lack of awareness of available service discounts for seniors and persons with disabilities who use public transit.
- Acceptability-Public fixed route transportation is often intimidating to those that have never used public transit.
- Acceptability- The poor use of signs to convey information both at fixed route transportation stops and on the buses themselves presents a barrier to full utilization. There is limited use of audio announcements about routing and stops that would support easier use of public transit by persons with sight impairments.

#### **Program Based Transportation**

Program based transportation is specialized transportation provided to a person as part of the individual's participation in another service program such as senior center services or a Community Services Board (CSB) program. Often the transportation provided is the critical ingredient in the person's ability to participate in the service. FASTRAN is by far the most significant provider of program based transportation services to persons in need of long-term care services in Fairfax County.

FASTRAN provides over 300,000 one-way trips to individuals with mental retardation that allows participation in various work, education, and rehabilitation programs sponsored by the CSB. FASTRAN also provides an additional 49,000 trips for persons with mental illness for similar programs and services. In terms of transportation service performance, currently 93 percent of CSB program-based trips meet on-time standards and there is less than one formal complaint for every 5,000 trips.

The County's senior center program is also supported by FASTRAN. Individuals 55 and older (except aged 60 and older for Bailey's, Groveton, and Gum Springs senior centers due to a federal grant) are transported to and from the County's 13 senior centers. In addition FASTRAN supports a small number of community based senior center programs targeted at specific cultures. The senior center program provides seniors an opportunity to socialize, participate in a variety of educational and recreational activities, and have a nutritious meal. In FY 1999, FASTRAN provided 104,499 rides to senior center program participants. In addition, FASTRAN provided an additional 2,135 rides for clients of the County's Therapeutic Recreation program.

### **Gaps: Program Based Transportation**

- Availability- There is a periodic waiting list for transportation to some senior centers, mainly at the western end of the county, due to route capacity.
- Availability- Specific nationalities have access to a senior center program targeted to their nationality only one day per week, largely due to transportation availability limitations.
- Acceptability- Senior center participants are asked to voluntarily contribute \$1.00 per round trip, but are not required to pay based on the Older Americans Act. This can generate confusion around the true affordability of senior center participation.
- Acceptability- While overall on-time performance for CSB program related trips is generally good, some overall travel times can get lengthy due to the location of the program in relation to the participant's residence. This is the result of having relatively unique programs located in one area of the County.
- Accessibility and Acceptability- Seniors do not have a choice of center selection. They must attend the center that is closest to their residence. In some cases, participants will not go to a particular center because the population served is generally more frail while another center's population is more "active." Transportation between center catchment areas is not permitted (with the exception of seniors attending a special senior center geared to a particular nationality). Individuals that live near Bailey's, Groveton, and Gum Springs senior centers cannot attend a senior center until they reach the age of 60 due to a federal grant restriction on these centers and will not be transported to one where the eligibility criteria is 55 years of age.

Program-based transportation provides the foundation infrastructure on which other paratransit services are built. However, the supremacy of program specific requirements and resource utilization generates gaps in other dimensions of the FASTRAN operation.

#### **Critical Medical Transportation Services**

FASTRAN provides transportation services to individuals who must undergo continuing dialysis, cancer treatment, or rehabilitative services. Service is only provided on a space available basis. In FY 1999, FASTRAN provided 17,803 critical medical transportation rides. Service is only available Monday to Friday, between 10: 00 a.m. and 2:00 p.m. FASTRAN regularly transports individuals to 11 dialysis centers in the area. It takes four working days to schedule transportation to a dialysis center. All individuals must complete an application to determine their fee (between \$2 and \$5).

#### Gaps: Critical Medical Transportation Services

Availability - Based on a FASTRAN telephone survey of 70 clients in need of transportation services to and from a dialysis center, only 25 persons were able to secure a round trip. Twenty-one persons were able to secure even a one-way trip. Twenty-four persons were required to secure other means of transportation to their appointment because FASTRAN could not even partially accommodate their needs.

- Accessibility It takes four working days to schedule transportation to a dialysis center.
- Accessibility and Acceptability Individuals in need of transportation for cancer treatments and rehabilitative services must schedule their appointments during midday (non-peak hours 10:00 a.m. – 2:00 p.m.) to reduce the probability of denial of transportation services.
- Acceptability FASTRAN will not transport individuals to appointments for critical medical care outside the County because of the impact such trips have on bus availability for other services.

#### **Dial-a-Ride Services**

FASTRAN provides transportation services to low-income residents of Fairfax County for medical appointments and essential shopping needs. An individual must be within 225 percent of the federal poverty guideline and be certified. Individuals are restricted in the time that service is available (10:00 a.m. to 2:00 p.m., Monday to Friday). An individual is required to schedule the trip one to seven7 days before the trip is to take place. Riders are required to be ready 15 minutes before and after the scheduled pick-up time. Each area of the County is assigned a single specific day of the week for grocery shopping. In FY 1999, FASTRAN provided 27,305 one-way trips for 2,821 clients. Approximately, 57 percent of the riders were seniors.

#### Gaps: Dial-a-Ride Services

 Availability - Dial-A-Ride services are restricted to 10:00 a.m.-2:00 p.m. Monday through Friday for limited purposes. The January 2000 Needs Assessment conducted by the Fairfax Area Disability Services Board concluded:

For those with disabilities, the limited time availability of FASTRAN ... makes it even more difficult to get appointments. Many medical appointments simply do not end early enough in the afternoon to let people catch the last run that FASTRAN provides. Also, FASTRAN is unavailable in large areas of the County.

- Accessibility- All program information is in English only, which limits access to individuals who do not speak or read English. Based on the most recent Fairfax County Household Survey, over 30 percent of County households speak a language other than English at home as the primary language.
- Accessibility Lower income individuals and others may not access the service if they have incomes above 225 percent of the federal poverty guideline:

Family Size	225 percent Annual Income Level
1	\$18,540
2	\$24,885
3	\$31,230
4	\$37,575

This forces other low-income individuals to use more costly, less acceptable transportation alternatives.

Acceptability - The service significantly limits trip purposes.

It should be noted that in FY 2001, FASTRAN will conduct a small pilot program to expand the Dial-a-Ride program. This expansion will increase regular Dial-a-Ride peak trips and eliminate restrictions on trips in the following planning districts: Springfield, Rose Hill, Mount Vernon, and Lower Potomac. This pilot will address, in at least a limited fashion, some of the gaps noted above.

#### **MetroAccess - ADA Transportation**

MetroAccess is the regional paratransit system established by Metro and its member jurisdictions, including Fairfax County, in compliance with the American's with Disabilities Act (ADA). The cost of a trip (anywhere within Metro's operating area) is a flat rate of \$2.20 one way. FASTRAN is currently a local provider for ADA rides in Fairfax County. In FY 1999, FASTRAN provided over 16,500 MetroAccess rides. Other vendors also provided Access rides to Fairfax consumers. MetroAccess serves only those clients determined to be ADA eligible. The eligibility process usually takes three weeks to complete.

All requests for MetroAccess rides must be called into the MetroAccess offices, which then are assigned by Metro to a designated transportation provider. An individual may be transported in one direction by FASTRAN or cab and then be transported in the other direction by another provider. Individuals riding long distances in the metropolitan area may ride one segment with one provider, another segment on Metro Rail, and a third segment by a third provider.

The Fairfax County Board of Supervisors held a MetroAccess Public Forum in October of 1999. One hundred people provided testimony. This forum shed significant light on the issues and gaps related to this service.

#### Gaps: MetroAccess - ADA Transportation

- Availability MetroAccess only serves the areas of the County served by WMATA.
   Pick-ups must be within three-quarters mile of a fixed MetroBus route or MetroRail station.
   Parts of Great Falls, Chantilly, Clifton, and Gunston are not served by Metro transit or MetroAccess.
- Acceptability Using multiple providers often confuses consumers who are never sure who will be providing the trip. Since Access is a "curb-to-curb" service rather than door-to-door or "door-through-door" service, patrons must look out for a vehicle coming to pick them up and may often miss the ride due to confusion.
- Acceptability MetroAccess has had significant reliability problems with respect to on-time pickups/arrivals, no shows, and/or stranded passengers. Over 52 percent of the MetroAccess Public Forum participants had negative comments related to reliability.
- Acceptability The MetroAccess eligibility process takes too long (three weeks) and requires a burdensome medical certification that can only be obtained in a very limited number of locations (currently only Mt. Vernon Hospital).

- Acceptability Trips must be booked at least a day in advance. There is no same day service.
- Acceptability Consumers must provide their own personal care assistants as MetroAccess does not provide them as part of the ADA service.

Consumers of Metro Access services who require that they be accompanied by a personal assistant during their trip are required to provide their own even when assistance is available at both ends of the trip. This adds both financial and scheduling hardships to obtaining transportation by requiring payment for a personal assistant for the trip when they may not be needed for the actual purpose of the trip, and scheduling the assistant as well as the trip.

### **Informal Transportation Resources**

These include trips provided by churches, senior residences, non-profits and volunteer groups, etc. There is little known about capacity and availability of these transportation resources. The 1999 senior transportation study group attempted to survey these providers to learn about the extent of this resource. It was learned that some transportation is provided. However, the relatively few respondents in each category precludes drawing major conclusions about capacity and availability of this type of resource.

#### **Gaps: Informal Transportation Resources**

- Availability There are significant awareness gaps regarding these loosely organized and ad-hoc services. More needs to be learned about who is providing what kinds of transportation services.
- Accessibility There is no mechanism to coordinate these resources. In some instances, providers of these types of services do not want to coordinate in a larger transportation network for fear of inundation, and internal program rules regarding usage of transportation resources.

#### Systemic Issues

Some of the most troublesome gaps in the transportation system for long-term care clients do not relate to a specific mode or provider of transportation. Rather, they are systemic gaps, applying to either the whole system or significant segments of the system.

# Gap: Awareness of the availability of existing transportation service resources

 Availability - Regardless of the other types of gaps that are present in the transportation services arena, there is an overriding gap in awareness of available transportation services among both the elderly and persons with disabilities. In 1999, a County staff workgroup commissioned by the County Executive to look at transportation issues affecting the elderly concluded that:

Despite the vast array of public transit services in the community, it is difficult to learn what services are available within a given community...

Those who, for the first time, find themselves in need of some form of transportation assistance, find they must navigate a variety of different information and service resources for the various types of transportation services. There is no comprehensive source of information where individuals can go for assistance in developing an individual transportation plan.

The issue of awareness becomes more complex where it becomes important to connect both informal and formal transportation networks (family, volunteer groups, FASTRAN, public transportation, MetroAccess etc.) in order to meet complex needs. Further, services providers (transportation and otherwise) are often unaware of the range of transportation options that are available for the elderly and/or persons with disabilities.

This awareness gap results in an inefficient use of existing transportation capacity, masks true demand for transportation resources, and exacerbates other gaps as persons use less than optimal transportation resources or face the problems associated with transportation isolation.

# Gap: Complex and fragmented application and certification processes for transportation resources

 Acceptability - Each of the major (and often minor) sources of transportation assistance has a unique application process and eligibility criterion. This requires consumers to navigate multiple application processes at varying locations.

There are generally no linkages between transportation application processes. At times, there is a long wait time between application for and authorization to use transportation services (three weeks in the case of MetroAccess). MetroAccess requires a medical disability certification that can only be obtained by visiting Mt. Vernon Hospital. There is little or no use of "presumptive eligibility" (assuming someone is eligible based on declaration while the formal certification process is conducted) or cross-program eligibility (if you are authorized for one service you are deemed automatically eligible for another) in the transportation services arena.

# Gap: There is currently no transportation service that is systematically designed to provide "transportation respite" to caregivers

 Availability- Family and other caregivers are the primary source of transportation assistance for many long-term care clients. They bear the brunt of critical and noncritical medical transportation needs, transportation to socialization and recreation activities, as well as transportation for shopping and other trips.

Arranging back-up transportation is often difficult when caregivers wish to take a vacation, become unavailable for transportation assistance due to illness or injury, or are unable to otherwise provide assistance on a one-time or temporary basis. Commercial alternatives to family provided transportation (cabs, etc.) may present affordability and/or appropriateness problems.

# Gap: Lack of optimal utilization of existing transportation resources. Lack of programmatic coordination to optimize transportation resources

Currently there is no mechanism in place that supports the optimization of the array of specialized and general transportation services that are available to seniors and persons with disabilities in Fairfax County. In addition, better human service program coordination (in terms of location and scheduling) could help better utilize existing transportation resources.

- Availability There is an intense peak hour (early AM and late PM) demand for specialized transportation services (particularly FASTRAN) that severely constrains the availability of transportation assistance. Program start/end time shifts could help alleviate some of the capacity problems inherent in the current system. Looking at service and program start-times with an eye to cross-system transportation planning could relieve some of the demand pressure.
- Accessibility Many of the programs that serve persons with disabilities for which FASTRAN provides transportation are located in one general section of the County. This creates a peak hour flow of a large number of buses moving to that part of the County. This results in longer consumer ride times and less bus availability in other parts of the County at certain times of the day. If there could be greater variation in program location, ride times could be shortened and buses would be in a better position to provide other forms of transportation or to manage other riders along with the various program participants.
- Accessibility There is only limited use made of the "hub concept" in planning transportation routes for both demand responsive and specialized program transportation services. Additional capacity may be derived through expanded use of this strategy. In addition, there is limited linkage between specialized transportation services and fixed route services. Additional capacity may be generated in the use of existing transportation resources by connecting trips between fixed route and specialized transportation systems.

# Appendix B

# **Fairfax County Long Term Care Task Force**

## **Asset Analysis**

At its meeting of November 2000, the Long Term Care Task Force complimented its analysis of the gaps in the continuum of long term care services by brainstorming a list of assets that exist in Fairfax County which could be harnessed to address the gaps. The list generated at that meeting is reproduced below. The assets were categorized after the meeting:

#### **Human Assets**

- Highly educated people
- Large population of volunteers
- Federal government workers who work on long term care issues
- An influential delegation of Northern Virginia legislators
- Expertise of the diplomatic community
- County staff abilities
- Strong advocates in the community: seniors, disabled, family members, and caregivers
- Families providing long term care
- Disabled people
- Individual providers of long term care and the services they provide
- Baby boomers at their peak earning, skills, productivity, abilities and interest
- Caregivers
- Many volunteer organizations attuned to community needs
- Retired military
- New class of wealthy people who have not decided where they will commit their money
- Vital active seniors
- Community of people needing long term care

#### **Organizational Assets**

- The Long Term Care Task Force
- Housing Authority which is interested in affordable housing
- Universities
- Union headquarters
- County government database
- Alzheimer's Association
- AARP
- ARC
- NACO
- Commission on Aging
- Disability Services Board
- NARFE
- United Way

- Citizens Coalition for Nursing Home Reform
- Chamber of Commerce
- NVRC
- COG
- Federation of Civic Associations
- Headquarters of the Population Center and the Independence Center
- National Council for Independent Living

#### **Physical Environment Assets**

- Diversity
- High average income
- Technology corporations
- The Faith community
- Multi-national businesses that can draw resources
- Business community with an interest in long term care issues
- Highly skilled and competent health system hospitals and paraprofessionals in the health care field
- Long term care infrastructure of the County
- National association headquarters
- Transportation infrastructure
- Media outlets
- Climate
- Large number of community-based and grass roots organizations
- · Nursing homes, retirement communities, assisted living facilities
- Military
- Excellent communications infrastructure
- · Large number of consulting firms
- Professional associations
- Good housing stock
- Numerous studies and analyses
- Parks and recreational areas
- Pride in achieving excellence
- Civic associations
- · Aging and disability network which communicates and works together
- Many homes with internet access
- Strong capable networks with many volunteers
- Assisted technology loan fund for people with disabilities of moderate to higher income
- Good educational opportunities for workforce
- Proximity to DC, national government and organization researching long term care issues
- International airport

#### **Political Environment Assets**

- Responsive local government
- Olmstead decision creates opportunity for funding long term care in the community

- Visit-ability tax break passed by state government
- ADA and Fair Housing Act has created legally enforced accessible housing options
- A strong desire to live in the community among the elderly and persons with disabilities
- People who work in industry are ready for change
- Consumers not happy with the way things are
- Not a corrupt community